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UNIVERSITY OF ALBERTA

VOICES FROM THE INSIDE: SCHOOL EXPERIENCES OF PEOPLE WITH DEVELOPMENTAL DISABILITIES

BY

HEATHER RAYMOND

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements of the degree of Master of Education.

DEPARTMENT OF ELEMENTARY EDUCATION

Edmonton, Alberta

Spring 1995

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UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled "Voices From The Inside: School Experiences of People with Developmental Disabilities" submitted by Heather Raymond in partial fulfillment of the requirements for the degree of M. Ed. in Elementary Education.

Dr. D.J. Clandinin

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Dr. Julia Ellis

Date: April 3, 1995

ABSTRACT

Seldom have people with developmental disabilities had their way of knowing shared. This narrative inquiry describes the lived and told school experiences of two individuals who have been labeled developmentally disabled . This study includes the reconstruction of my story as researcher, special education teacher and regular education teacher along with the two research participants' reconstruction of their experiences of being in school.

Data was collected through extensive conversations between the researcher and two participants. The participants were invited to tell their stories in their words in order to allow them to control and develop their own responses. The space was created for the participants to tell and retell their own school stories. The inquiry is represented and given meaning from the conversations with the participants. Three narrative accounts are presented: my account as a teacher and the two participants' accounts as students.

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CHAPTER ONE

Introduction

Researchers, such as Kirby and McKenna (1989), suggest our experiences and understandings should be part of our research. "This means that we must invest part of ourselves in the process of creating new information. We are an ingredient of our own research" (p. 7). As I struggle to imagine myself as a researcher I, like Kirby & McKenna, (1989) feel that my research self, teacher self and friend self overlap and it is the blending of these experiences that color my search.

Hollingsworth (1990) speaks about the need for the researcher to be vulnerable and be "cast in as critical a perspective as the researched. The investigator is not an invisible, anonymous voice of authority, but appears as a real, historical individual whose beliefs and behavior must be open to critical examination" (p. 4). "In this way, the researcher is incorporated into the research and is not left hidden from the process" (Kirby & McKenna, 1989, p. 43).

Peshkin (1988) holds the view that the researcher's subjectivity is in operation throughout the research process. He encourages researchers to systematically identify their subjectivity as they conduct their research. "...one's subjectivity is like a garment that cannot be removed. It is insistently present in both the research and non research aspects of our life" (p.17). He suggests that identification of ones' subjectivity permits the researcher to be attentive to its potential to be enabling and disabling throughout the research process.

Therefore, the starting point of my research begins with my own narrative (Clandinin & Connelly, 1994). Though the development of my narrative I am accounting for myself (Malker, 1991). The construction of my own narrative has

helped me to locate myself in the research while forming the research parameters. My experience is at the center of the research and I choose not to deny or hide this fact. My narrative is important because my search for the research concern has not come out of a vacuum, but has emerged from my own experiences, as well as from the minimal presence of the "topic" in the research literature.

The writing and sharing of my narrative has helped me to dismantle my past and to reimagine a different future (Heilburn, 1988). As Witherell & Noddings (1991) say "(s)tories invite us to know the world and our place in it" (p.13). It was through the telling and retelling of my story that I gained a better understanding of my relationship with my students' parents. This telling and retelling of my story created the tension for the possibility of reliving my story. The retelling gave way to a reliving that speaks of changed actions. Connelly & Clandinin (1994) refer to this reliving as a transformation.

My research is a continuation of my telling of my lived, told, retold and relived story. The research is an opportunity to look further into my relationships with people with developmental disabilities. I am as much seeking understanding of myself as I seek the research participants' understanding of their lived experiences in school. By being engaged in narrative inquiry with the participants I see the possibility for further awakenings and transformations; personal-growth is an ongoing process. To begin the relationship between myself and the participants I see the need to willingly share my own narrative before I ask the research participants to share theirs'. By doing this, I change the traditional power dynamics of the hierarchy which tends to exist between the researcher and those who are researched. The researcher becomes another subject in the research process and another dimension is added to the data (Kirby & McKenna, 1989, p. 60).

It is important for me to share before you begin to read my narrative that it has taken me a long time before I felt safe to focus on my own growth as the beginning of my research.

> You can know me truly only if I want you to know me. If you want me to reveal myself, first demonstrate your good will - your will to employ your powers for my good, and not for my destruction (Jourard in Purkey & Novak, 1984, p. 58).

With this I welcome you to read my story.

Narrative Beginnings

I began working in the helping profession because of a grade nine teacher who once said to me "You'd be good working with people because you are so caring." I believed I was caring when I started. My first job after graduating from college was working in an institution with children labeled developmentally disabled. My time in this place was short in comparison to the time the children spent. I left after eleven months looking for a better place. They had to remain behind to live out their lives in isolation, locked away from the view of society. Even today after seventeen years some of these children, now adults, still live in this institution.

I moved to Alberta and worked in a treatment home for children labeled developmentally disabled and who had severe behavioral difficulties. I had my first contacts with families and wondered why they couldn't be as skilled as "we" the professionals in controlling their children's behaviors. In reflection, I now see how naive and arrogant I was. Within three years I moved from being a group

home staff member to being a behavior consultant to parents, and later to a middle management supervisory position. My career as a professional was well on its' way.

At the end of three years working at this agency, I returned to schooi to get a degree. I chose teaching because it was a way to further my career. I could build on my knowledge of working with people with developmental disabilities as I worked towards a degree in Special Education. My sense of my self was that I was an expert. This was reinforced in many of my classes at the university, especially in the Special Education course for I was training to be a specialist, not a generalist.

The Professional

Upon graduating from university I was hired as a special education teacher. I was responsible for the education of nine students labeled autistic and for the supervision of four program aides. I was also the lead special education teacher in the school. In my last year of teaching at this school, I was determined to have some of my students move out of my special education class. It was a class I deemed very restrictive because there was a ratio of one adult to two students. I envisioned the students were ready to move on, to progress to the next step in the continuum of special education. The next step was into a classroom where the student/teacher ratio was ten to two. It seemed a logical move for it to fit into the bureaucratic framework of special education, that is, students progress through the continuum of options when educators believed the students were worthy of such a move.

I presented my idea to the principal. With his approval I contacted the district placement consultants for assistance in determining where the students should move. Meanwhile, I slowly and cautiously expressed my plans to the parents. I maneuvered carefully because I didn't want any opposition to this idea since I was a professional and knew what was best for their child educationally. Things went smoothly and the students, with the assistance of the program aides, began to attend different programs around the city to determine which one would best meet their needs.

Mrs. D.

A roadblock appeared. One student's parent, after visiting all the potential programs for her son, contacted the school and indicated she did not approve moving her son to any of the programs offered. She indicated that if he was to move out of the present special education program, he was going to attend his neighbourhood school. I was aghast at such a suggestion. Her son was never a student we considered for even partial integration so how could she expect him to succeed in a fully integrated setting.

I did not take Mrs. D. seriously and continued to pursue placement options for her son. A meeting was scheduled to "sell" the idea of having her son attend the local segregated high school. The school principal invited a parent of one of the high school students to assure Mrs. D. that this was the best place for her son. I remember Mrs. D's. anger that we had set up the meeting in this manner. She indicated to the parent that she appreciated him taking time off work and that she was in no way critical of his decision that his son attend this school but it was not what she wanted for her son. The meeting went from bad to worse and we all left with an unpleasant feeling.

I came home and shared with my husband my frustration about Mrs. D.'s unreasonable request. I was adamant that I was not going to help her secure an integrated setting for her son because, as a professional, I knew that this was wrong for him. I wonder now what Mrs. D. said about me when she went home to her husband.

Moving On

The school year ended. Five of the six students we planned to transfer moved to alternate special education classes. Mrs. D's. son stayed behind. I was encouraged to apply for a consulting position and was successful in my application. This reinforced my sense of being an expert for now my title exemplified it. I was to be an Educational Behavioral Consultant the following year.

A Crack In The Armor

The next year at Teachers' Convention a charismatic speaker named Dr. Marsha Forest spoke of how schools were designed to exclude rather than to include individuals with developmental disabilities. During her presentation she brought me to tears, something that never could or should happen at Teachers' Convention - an environment in which we sampled new ideas but were not affected by them. I have tried to recall what she said that day that caused such an emotional reaction but I do not have a vivid memory of it. Rather I have a sense that her words of how schools reject people with developmental disabilities reflected me, a special education teacher who believed in the status quo.

Throughout this presentation I was reminded of Mrs D. and the way I had responded to her request for her son to go to his community school.

Mrs. D. Revisited

I approached Dr. Forest to tell her how I felt about her presentation. She told me I should contact a Mrs. D. for she needed some assistance in securing an integrated placement for her son. Mrs. D. had attended a two day session by Dr. Forest for parents prior to Teachers' Convention and had also spoken to Dr. Forest. I went home numb. I wanted so much to figure out what integration meant. To have the chance, I would have to contact Mrs D. I remember making the phone call was very difficult. I knew I had to do it. I can not remember the conversation but I do remember Mrs D's. genuine welcoming of my assistance to help her son to be included in his community school. She taught me a valuable lesson about forgiveness that day.

Partnership

The following month, Mrs. D. on her own, had secured a high school placement for her son for the following September. I was contacted by the vice-principal of the school on Mrs. D's. recommendation and was invited to assist the school in planning for his inclusion. I was excited and nervous for I had the feeling that, as the specialist, I was expected to be the expert. It wasn't long before I realized and learned from the modeling of Mrs. D. and the vice-principal that to be successful in our endeavors it was necessary to work together in a mutual and reciprocal helping relationship. I was not viewed as the expert but as a member of the team. We did not yet have the skills or knowledge to ensure

Mrs. D's son's successful integration. It required an innovative plan and this would be best accomplished by working together.

Touching Of A Heart

Although I found I was not required to be the expert, I wanted to learn more about what other people thought about integration. This led me to attend the McGill Summer Institute on Inclusive Education. Dr. Forest was a visiting scholar.

At McGill I sat as a member of a class of twenty-five eager learners gathered from all over the world to hear the wisdom of three women, one who had only the ability to move her thumb. I had come with a sense of new beginnings but was unaware of what awakening I would experience in the next two weeks.

The first day went smoothly with reflections on where we had come from and what our identities were back at home.

The second day started with Dr. Evy Lausthaus, a professor in Special Education, sharing with the class the story of the birth of her daughter, Hannah. Evy, who had discredited other parents as valuable members of the education team, was now the mother of a disabled child. Hannah was born with Down Syndrome. Evy described how family members reacted with differing degrees of horror to the reality that Hannah was disabled. Reactions ranged from one aunt saying that she could not bring herself to finish knitting the baby sweater to some members sitting a modified shivah to mourn the burden this child would bring to the family.

Evy's story led to her involvement with parents who could not bring themselves to parenting a child with Down Syndrome; to her opposition to the medical promotion of 'amniocentesis' to permit the aborting of unborn children identified as having Down Syndrome; and to her opposition of the euthanasia practices around children born with Down Syndrome. Throughout her account she brought the ideas back to her daughter, a valued member in her family.

As she spoke my mind was filled with rambling thoughts. I saw myself as the professional who did not include parents. I was incensed by Evy's family's rejection of Hannah. I wondered how I would react if I gave birth to a child with a disability. Would I consider having amniocentesis to determine if a child I was carrying was disabled so that I could abort it? These thoughts had never before clouded my professional view of children with developmental disabilities. I was unable to resolve my dilemmas through the discussions that followed and took my doubts to lunch.

The discussion from class flowed into the clusters that formed in the various eateries. I had joined Judith Snow, the woman who could only move her thumb, and a few others for lunch. The lunch dialogue was candid and I shared my disgust about Evy's family's rejection of Hannah. I also stated that I would consider having amniocentesis and possibly abort the fetus if the child was disabled. This statement brought much heat to the discussion. Throughout it, Judith remained a passive observer.

We went back to class, painstakingly going up the hill with Judith negotiating the traffic in her powered wheelchair controlled by her thumb. In class we quickly returned to the morning discussion and explored our views and values in relation to Evy's story. Many of us spoke of these issues but remained impersonal in our professional way. Close to the end of the day Judith, who had remained silent till this point, said in her dry raspy voice, "Someone sitting right

here in front of you has said she would consider amniocentesis. I want her to realize, if she aborts a child, that child could have been me." Immediately the tears welled in my eyes and I could not control them. Why? Because that person was me. I saw myself as an advocate for people with developmental disabilities. What did this statement say about me? I would be an advocate but I sure as hell did not want a child like that! I felt sick. A feeling of dread flowed through my body. I realized in a fraction of a second that I was not the person I believed myself to be.

I left the class in a fog, never having anticipated that my values would ever be challenged in a university class. This class was supposed to be a theoretical session on how to integrate children. I did not need to consider my own actions in this. I just wanted the recipe.

I made the 30 minute walk back to my residence for my two week stay in Montreal, with tears in my eyes and unable to describe why it was happening. I was wrestling with everything that had gone on in the last 6 hours. I felt as if my whole being had been turned upside down. I did not know which way was up. I tossed and turned all night.

Wednesday was rough. I returned to class with a feeling of unease. I felt I had failed Judith and Marsha, two people I admired, two people I was getting to know. I wanted them to like me. I knew I had to be there. I could not run away even though I knew I would cry. I could not stop the tears; it was as if a valve had been opened and could not be turned off. I did not know what I believed in. I felt stripped of my identity, "Special Education Teacher." My words and actions were incongruent. I knew what to say but I didn't live what I said. I felt as if I was in shock.

I quietly took my place among the other twenty-four students. I felt a part but apart as Judith began the proceedings for the third of the ten days we would be together. She took us on a journey, the journey of her life. She told us of her struggle to live in spite of medical professionals who said that she would not live past the age of thirty; of how she had been forced to live in a geriatric ward to receive the custodial care she needed; of how nursing staff forced her to choose between using the washroom or being fed because of her insistence on working outside the hospital; of how her arrivals and departures did not coincide with the hospital routines for meals, and of how she was starving to death because of this treatment. She wove the horrors of her life into her determination to survive.

Judith said things that morning that were profound. Her story helped me to start to deal with the way I was feeling. Judith said that everyone is different and the differences are critically important and at this time in history society has labeled her differences as a disability. She told us that, because of society's view, she has had to learn to be disabled. It had been imposed upon her and not something that was intrinsic. While she has now accepted this role that society has scripted for her, she does not allow it to constrain her. She thinks about being disabled but does not worry about it. She has taken control and has become the author of her own life. Her role as a recipient of services is only of minor importance in her life. In the telling and retelling of her story she has become a woman in control of her own destiny.

As I listened, I realized I had never before met a person with a disability who was intellectually as bright as or brighter than I. I had never had a person, who was perceived as devalued, tell me how they interpreted my way of helping. I realized that until then I could not see past the handicap, and, because of this, I did not want to give birth to a child with a disability. Subconsciously I saw people with disabilities as a burden, not as an asset to others.

I was ready to move forward. I was now able to see Judith before I saw her disability. This was important, for it has guided me through my journey of welcoming all children into my classroom and of being vulnerable in my discovery of how to do this. I was beginning to comprehend the complexity of family's daily struggles for survival in a world of on going rejection. I had forgotten these were real people. I began my career in special education because I wanted to help people. Meeting Judith reminded me of my neglect and of my sidetracked commitment to respond genuinely to the individual rather than to the system structured around them. I also realized there were some very fine people buried in bureaucracies and I was one of them. It was my heart that needed to be touched, not my professionalism, in order for me to grow as an educator. I was now ready to be receptive to relationships with children with developmental disabilities and their parents.

Caring Put Into Action

When I returned from the summer institute, it did not seem enough to be part of the caring team to support Mrs. D's son's attendance at his community school. I felt I had to do more. As in the CBC-Radio Ideas series titled "Blue is the Color of Hope", January 6 & 7, 1993, Martha, the woman being interviewed shared in response to those that helped her to be released from prison, "You can't pay it back. You can only pass it on." I too was searching for ways I could pass it on. I called Adele, a parent of another student I had taught. I asked her if she had ever thought about having her daughter attend her community school. I wanted to stand beside other families in their requests for a different world for their children. I began to realize that to be in solidarity with families, it was necessary for me to enter into the situation with them (Freire, 1970) and not just

to talk about support and what that might be. Adele and I decided to ask the school to allow her daughter to attend her community school. We arranged for a meeting in September. It took a year with Adele doing most of the on site work. We talked on the phone about what needed to be done at every step. Her daughter went to her community school the next year.

My need to understand the perspective of families with children with developmental disabilities led me to joining a number of parent groups that advocate for the right of individuals with disabilities. I could no longer remain removed and rationalize my action as a conflict of interest. A conflict of interest to whom? I had used the rationalization to remain objective, a defense to stay separate from the families of the children I taught.

Years later at a weekend at Adele's family country home she asked me, "Why couldn't you be my friend when you taught my daughter?" As a student of Robert Coles said (in Coles, 1989) "...the answer was hard for me to admit, even to myself, never mind say to someone else!" (p.180). This question struck me deeply for I was ashamed of my answer. It has been hard to admit that at one time as a professional I felt it was necessary to remain distant from families with child with a disability in order to remain objective. Objective about what I wonder now.

Reflective Conversation

While at McGill, I had discovered my actions as a special education teacher contributed to maintaining students with developmental disabilities and their parents in an oppressed state. My view was that input from students and their parents was not necessary nor worthy of my attention. As a professional, I could determine what was educationally best for students. Parents' views were

to come through the correct channels (i.e., Individual Education Planning meetings, parent teacher interviews). To Heilbrun (1988) "(p)ower is the ability to take one's place in whatever discourse is essential to action and the right to have one's part matter" (p.18). Controlling where parent voices could be heard removed their power. Their input was peripheral, to be listened to but not necessarily heard. My actions in listening were a kind of "false generosity" (Freire, 1970). I demonstrated my "generosity" by hearing their concerns but I did not respond in action to them. This was the situation with Mrs. D. when she wished her son to go to his community school. Gartner (1988) gives a sense of this when he speaks of this phenomenon in his article titled "Parents no longer excluded just ignored."

The discovery that I contributed to the oppression of others was painful. As a professional I had become less gentle, less empathic, less responsive and less caring than I imagined. My reflections at McGill helped me to understand how integrating my past experiences with present experiences could in turn influence my future experiences. Connelly and Clandinin (1994) describe this experience as an awakening, a beginning of retelling my story. The retelling led to a transformation in my way of knowing in practice.

I now began to look at my relations with people with developmental disabilities. "If, as Gilligan and Miller claim, women tend to define themselves in the context of relationships, then it is not surprising that women making a break with their pasts and former relationships may enter a period in which there is considerable flux in self concept." (Belenky et. al., 1986, p.81). As I gave up my identity and connection as a special education teacher, I struggled with my ability to articulate my beliefs and my affirmations. My unease began in my relations with the class participants at McGill. Through the relationships with the instructors and participants, I recognized there were other possible stories for my

life (Connelly & Clandinin, 1994). Through the telling and retelling of my teacher story I had become aware that my notion of a professional was interfering with my openness to the students and their parents.

I had been cultivated to the professional norms and the awakening caused me to reflect on this cultivation and its impact on the stories I lived and told. I was aware for the first time I had been living a story of a professional, one that "...clearly implies a degree of power - the power to make decisions and the power to implement them, in ways consistent with the individual practitioner's knowledge and skills" (Savage, 1992 p. 47). This awakening gave birth to the idea that there were other possible ways for me to tell my story. The retelling was one of imagining myself as moving away from my affiliation with the professional to an affiliation with students and parents. This desire to tell a different story came about through the process of living and telling my story in connection with the class participants at McGill. I began to retell a story that was based on the morality of caring for the individual.

The opportunity to reflect on my practice (Schon, 1983) had awakened me to question my affiliation with the professionalization of my role as teacher. As a graduate student of Cole's (1989) shared "... we are always in danger of talking one line and living another - and the more successful we are, the more danger" (p. 125-126). As I became more successful as a teacher, I was further from my original reason for entering the teaching profession. Initially I had envisioned myself working in partnership with others to develop caring learning environments for the children in my classroom. I remember often saying that entering the teaching profession allowed me to use my knowledge of working with children in their homes. As a teacher I could use my awareness of their needs outside school and consider the whole child rather than just the segment of life they spend in school. However, once in the classroom I was resistant to

what was important outside of school, what their parents saw for their children. In my role as a teacher, I began to focus my attention narrowly. I was unable to interconnect the student's life outside and inside school. Although, I believed I was a champion of this idea I was not talking and living the same life.

Schon (1983) has noted that teachers perform their work inside formal bureaucratic organizations.

> Wherever professionals operate within the context of an established bureaucracy, they are embedded in an organizational knowledge structure and a related network of institutional control, authority, information, maintenance, and reward, all of which are tied to prevailing images of technical expertise (p. 336).

Noddings (1984) says some organizations reduce the capacity of one's ethical ideal. With the requirement of obedience to the organization's needs it reduces the individual's responsibility and reflection that is necessary for one to make one's own decision in caring. In this situation the individual becomes the instrument of another and the ethical ideal is diminished.

As I developed as a professional I viewed the organizational needs as more important than the families and their children. In order to effect the efficient operation of schools, as a teacher, I was required to adhere to certain beliefs within the system. This was particularly so if I wanted to be rewarded. My response to Mrs. D.'s request for her son to go to his community school reflected the system's organization and program options for children with developmental disabilities. To support Mrs. D. I would have had to question the organizational knowledge structure (Schon, 1983). This would be a threat to my affiliation with

expert professional. Telling a story that would reflect affiliation with parents and students was a potential threat to my association with the organization. In reflection I had begun to realize that my affiliation with the expert professional had diminished my ability for natural caring (Noddings, 1984).

My public voice was dominant in advancing the cause of the organization. I believe this requirement led to the erosion of my general caring and to the silence of my private voice. My experience at McGill forced this issue to the surface. "... the public world of reason and the private world of feeling and unjustifiable insight-were beginning to intersect" (Belenky, et. al.. 1986, p.125). Through this experience I allowed my private world to intersect with my professional world. By allowing this to happen I saw how I had been denying this private voice to shape my understanding of people with developmental disabilities. I realized to grow and to have an ethics of caring to guide my work I must be free to precede with the construction of the ideal and not be instructed as to what can be added or deleted. I believe that this is what I was faced while with working in the teaching profession. I was now faced with how would I retell my story in a way that allowed my private voice to be heard. I would need to come to terms with the side effects of the awakening (Connelly & Clandinin, 1994). I could no longer stay distant using my professional title as a defense for not being receptive to a relation with my students and their parents.

Schon (1987) believes that if we do not allow ourselves to be awakened to the taken for granted world, we are not open to new questions that can lead to new knowledge and a reconstruction of our knowing in practice. Only when we open up to what we know and allow ourselves to be surprised can we make new sense of our practice as teachers. My experience at McGill provided me the opportunity to reflect on myself as a practicing teacher. By reflecting on my own personal practical knowledge (Connelly & Clandinin, 1988) I became aware that

my values and practice were inconsistent. This coming to know my self as a practicing teacher was difficult because I had encountered a negative surprise. However, being open to the awakening I was then able to retell my story and hear a changing and evolving understanding of myself as a teacher (Miller, 1992).

Now that I had come to understand my work in a new way the system no longer made sense to me. I began to evaluate my knowledge about what I thought was best for people with developmental disabilities. What was my commitment? Now that I was able to tell a new story of my work with people with developmental disabilities, I wanted to be heard. There were risks as I explored the spaces in which to tell my story. I was scared. My story was not the story of the system. As Lisa, a student of Hollingsworth (1990), reported, she was "worried about survival at school -- because of personal differences instead of similarities" (p.17). I felt the same. My story was no longer one of expert professional. I wanted to engage in meaningful dialogue with parents in which there was parity between myself and those connected to the students. I wanted to hear what parents wanted and to help them achieve their hopes and dreams for their children.

I still struggle with Adele's question. Why couldn't I have been her friend when I taught her daughter? Why had I resisted meaningful dialogue with her? Had I believed that professionals did not have relationships with their 'clients'? Now I realized my actions indicated that I responded this way. I began to develop a receptiveness through an ethics of caring that allowed for the opportunity of natural caring to develop. My story with Adele has been one that asked me to reflect and reevaluate (Freire, 1970) my relationship to people with developmental disabilities. Now I try to live and tell a story in which I work

alongside people with developmental disabilities and not impose my beliefs and wants on them.

Reflections On The Purpose Of The Study

In my search for a research topic I had come to understand how I had been open to the listening of parents and what they desired for their children and how this listening had shaped my actions as a teacher. Further connections in my understanding of my actions and beliefs as a teacher I believed would come from hearing the voices of students who had been educated in special education environments. This (re)search has been an exercise in hearing the voice of students and reflection on my teaching through the eyes of my research participants. For the study of the narrative is not a study of oneself but "... a study of the individual in context" (Connelly & Clandinin, 1988, p. 79).

CHAPTER TWO

Introduction

As a beginning researcher I believed that research had long claimed that there is no time when tears and trouble are part of living. I started out my (re)search worrying that the view of a respectable researcher was someone who put a lid upon ones' personal practical knowledge, ignoring, hiding and surpressing it. It was not until I came upon the work of Jean Clandinin (1986) that I realized that there was place for my way of knowing in the research world. I had become aware, in this search, that telling stories about my personal practical knowledge was central in my way of knowing. What had come forth and was voiced in the telling and retelling of my awakening at McGill was a deepening understanding of my way of knowing; a way of knowing that was a narrative recounting, embodied in my senses. Judith Dereck (1989) describes for me why I believe the awakening I experienced at McGill was so powerful.

> No, she must be allowed to cry. It is only when women can experience her tears in the moment that she can also experience her true, deep feeling values in the moment. The tears of those young and capable women must be allowed and encouraged to flow - to flow out to the culture and society which so truly and desperately need them and their tears - to help society reconnect with the true and deep values of life which can substain and support that culture, that life, that of life in their society (p. 3).

It is with this new awareness that I realized that my "personal practical knowledge" (Connelly & Clandinin, 1988) and "way of knowing" (Belenky, et. al. 1986) had a valid and valuable place in the world of research. Narrative inquiry was a methodology that could help me find a place for my voice in the research world.

Narrative Inquiry As Method

> Humans are storytelling organisms who individually and socially, lead storied lives (Connelly & Clandinin, 1990, p.2).

Jerome Bruner (1986) proposes that there are two basic ways of knowing about the world: the paradigmatic or logical-scientific mode and the narrative mode. He argues that each mode provides "... distinctive ways of ordering experiences, of constructing reality. ...Efforts to reduce one mode to the other or to ignore one at the expense of the other inevitably fail to capture the rich diversity of thought" (p. 11). The paradigmatic concerns itself with logic, mathematics and various sciences that employ categorization, conceptualization and generalization as a way of knowing. In contrast, the narrative mode concerns itself with "...the vicissitude of human intentions" (p.16). He maintains that the narrative mode is built upon the human condition. The use of the narrative recounting as a way of meaning-making provides the opportunity to view one's experiences over time. This narrative recounting is a description of reality and allows one to see the truth in terms of concrete human experiences. My understanding of parents' desire to have their children educated in inclusive classrooms had been shaped by this latter way of knowing.

Narrativists believe that human experiences are storied experiences and that we basically live out stories and are story tellers (Connelly & Clandinin, 1990). Human experiences reflect a storied quality and it is the recording and the interpretation of these stories that interests the narrative inquirer. According to Connelly & Clandinin (1990) narrative inquiry "is the study of the ways humans experience the world" (p. 2).

Anthropologists have made us aware that to narrate is an apparent pervasive human need (Frye, 1986). Humans have

> "... the need to tell stories, hear stories, read stories; the need to make sense of lived experience through setting events in narrative relationship to each other. We use narrative to assess cause and effect in a pattern of significance, to relate ourselves to a sense of purpose, to claim a shared reality with other people, and to identify a specificity and a continuity of self through memory. In short we use the process of creating narrative shapes to identify our place in the world" (Frye, 1986, p. 18 & 19).

Robinson & Hawpe (1986) note that experience alone does not constitute narrative but it is the reflection on experience that helps us to construct stories. The stories that we tell are an attempt to account for our experiences and to make sense of them. Stories seem to be a natural way for us to recount these experiences. Sarbin (1986) suggests that human beings use narrative structures to think, perceive, imagine and make moral choices. Stories are reflective of the way we think narratively in our everyday life. The use of narrative in everyday life is a way to help us put order in human affairs. Discussion about episodes across

time is primarily narrative in structure (Gergen & Gergen, 1986). Many things are experienced retroactively and their significance is slowly clarified as we become aware of their role as we reconstruct our past in our narrative (Crites,1986).

Narrative inquiry opens spaces for those on the margins to tell their stories. These lived and told stories constitute experience (Connelly & Clandinin, 1994). In my (re)search I attempt to capture the experiences of the participants through narrative inquiry. Through the incorporation of the participants' views, I hope to further explore and better understand the morality of my teaching.

> We do not want to contribute to the public silencing of voices from the margins. Instead, we want to do research in a way that creates opportunities to reclaim and re-name that experience. We want methods that will enable people to identify and examine how living on the margin affects their lives, their opportunities, the way they think and act. In this way we can begin to focus on the social relations which daily help us to construct that experience. In particular, methods from the margins must focus on describing reality from the perspective of those who have traditionally been excluded as producers of research (Kirby & McKenna, 1989, p. 64).

The opportunity to share our lived experience with other people helps to give the teller the external confirmation that her life has significance. Adrienne Rich in Frye (1986) expresses it by saying, "...in breaking those silences, naming ourselves, uncovering the hidden, making ourselves present, we begin to define a reality which resonates to us, which affirms our being" (p. 61). Herein lies one of the critical conditions for the voices of differences to find their way to the centre

of the dialogue process. Through language we define ourselves, therefore it is important to create the space for all to be heard so that their voices do not remain forever silent or at the fringe of society.

Why Narrative Inquiry As A Methodology?

The purpose of this study was to give voice to the school experiences of individuals labeled developmentally disabled. In doing this I hoped to further construct my understanding of how my students may have interpreted my teaching. To do this it was necessary to conduct research that was grounded in the experiences of the individuals. My intent was not to silence the participants but to create the opportunity for them to reclaim and re-name their experiences (Kirby & McKenna, 1989). In selecting a methodology I wanted to find a way to allow the participants to describe reality from their perspective, a perspective that traditionally has been excluded in the production of research. I believe that they have different knowledge. As a teacher, I have a desire to understand this knowledge and way of knowing as I try to understand how best to educate learners that have been labeled developmentally disabled.

> Memories matter. They are our lives with our own personal pasts. They are ways of saying this is who I am... In looking back on their experiences, and remembering how life was for them, they are saying a lot about who they are now. They are people with a past, a past that has helped shape them. So often the pasts of people with learning difficulties have been discounted (Atkinson, 1990, p.36).

In my (re)search I hoped to create such a space by "build(ing) around an open and leisurely interview that establishes rapport and allows presupposition and frames of reference of the interviewee to emerge" (Belenky et. al. 1986 p. 10). Through the intimate interactions, rather than impersonal, formal, structured conversations, the voice of the participants can be heard. I invited the participants to tell their stories with few questions in order to allow the respondents to control and develop their own responses. The use of informal conversations created the space for the participants to tell and retell their own school stories. I strived to create an atmosphere that reflected being in conversation with the participants and not one of an interview. "In "real talk" domination is absent, reciprocity and cooperation are prominent" (Blenky et. al. 1986, p. 146).

Whose Stories Count?

Each of us has a story to tell, even those that society deems as developmentally disabled. When I discussed my research with others, I was often asked how could people with developmental disabilities tell their stories and how could it be trustworthy. I was often struck by such questions for I have come to see that each of us has a story. The stories of people with developmental disabilities may differ from mine but their stories also have pasts, presents, and futures and their stories are who they are.

> How after all, can one experience deny, negate, disprove, another experience? ... your experience is your truth. How can one being prove another being wrong? ... my being is my truth (Le Guin, 1989, p. 150).

As an educator, I had come to see that the narratives of people with developmental disabilities occupy the centre of my personal life. They are not individuals who live on the margin. They are my friends and my friends' children. Their memories count. I want to think about disability in terms of how the person with a disability narrates her school life.

> In new roles in new settings, more and more people with developmental disabilities emerge as having the same desire to author their own lives as anyone else does (O'Brien & Lyle O'Brien, 1993, p. 7).

Research Story

Asher (1991) working with women married to alcoholic husbands described her discomfort with her participants casting her in the role of rescuer. In a follow-up interview, one informant shared that her husband had beaten her up the previous week and that he was acting funny on the eve of the second interview. Asher asked if she could help by calling her at her home after the interview to see if the informant was okay. The informant said "no," but asked for Asher's phone number just in case. Asher decided to give the informant her office number rather than her home number. Telling the informant that she could call any time to "just talk", Asher rationalized this action by stating, "By doing so, I felt as if I gave her support but avoided becoming her immediate rescuer or counselor, a role I saw as incompatible with my role as researcher " (p.202). Asher (1991), goes on to describe how she guarded against becoming connected.

> Since I would be interviewing these women a total of three times over slightly more than a year, my perception of the importance of not divulging much personal or professional information about myself was connected to an increasing tendency on the part of the respondent to get to know me a little more at each wave of interviews. If they asked if I was doing this study for a thesis or a degree, I simply said, "Yes." If, after the interview, they asked me questions about my personal circumstances, I diverted the conversational focus away from myself. For instance, one women asked me, "What does your husband think of you running up here (40 miles) all these nights doing interviews?" Rather than saying that I was divorced, I simply smiled and said, "Well, it can get a little hectic sometime." (p. 202- 203).

Asher describes her struggle with her desire as a woman to give advice and assistance. However, as a researcher she felt if she gave advice to the participant this would influence the future of the participants' life and, in turn, would distort the research data.

As a researcher, I find Asher's perspective of the research relationship uncomfortable. Oakley's (1981) phrase "no intimacy without reciprocity" (p. 49) suggests a closer sense of what I have found in my research with the two participants. Oakley, from her own research experience, feels that interviews are a one-way process. She asserts that the traditional interview method as presented by Asher creates problems for interviewers whose primary goal is to validate the participants' subjective experiences. I viewed myself in the research

process as more than an information-gathering tool. I had a need to be in dialogue with the participants rather than to be in a pseudo-conversation that had boundaries set before the interaction. To be open to my teaching being further influenced it would be necessary to develop opportunities to enter into dialogue and engage in a process of reflection while allowing the participants to share their lived experiences in an open and free manner. An open-ended conversation created the space for my research participants to say what was important to them.

To use a traditional interview approach would have contradicted my need to abandon the "professional" role and to be open to honest relationships with others. I believe I could have professional competence while allowing myself to be lost in the potential of a relationship occurring outside the research process. To remove the potential of further involvement by remaining friendly but not revealing any personal information about myself seemed ridiculous. Oakley (1981) poses that "... the 'proper' interview appeals to such values as objective, detachment, hierarchy and 'science' as an important cultural activity which takes priority over people's more individualized concerns" (p. 38). I had discovered in my personal awakening that it was primarily through the dynamics of dialogue with parents that I was able to break through the definitions of experiences provided by the dominant educational discourse and come to see another way of understanding parent's lived experience and desire for their children. This desire to be in open-ended conversation with my research participants was what was central in the selection of narrative inquiry as a the methodology of choice.

Conversations: The Basis for Data Collection

Conversations between myself and the participants formed the basis for the data collection. The conversations can be described as being interactive in nature (see appendix "A" for samples of the conversations). Oakley (1981) suggests that in an interactive conversation the researcher is more than an instrument for data collection. Rather, both the researcher and the participant are considered a source of information. Therefore, we both shared information and contributed to the research process. The conversations were the sharing of ideas, philosophy and experiences. The conversations were a sharing of ourselves.

Intensive conversations as a methodology provided me with the opportunity to discover information about the participants' experiences in their language. Their voices allowed me to further reflect on my commitment to examine critically my lived experience as a teacher by reflecting on their telling of their lived experience. I was attentive throughout the many conversations to create a sense of equality between myself and the participants. One way this was accomplished was rather than having a set of predetermined questions to guide our conversations, I relied on spontaneous questions that occurred in conversation to further explore the participants' experiences. This created space for the participants to shape the conversations.

Setting The Table

The words of Brillat-Savarin (1985) best describe how I hoped to contribute to the creation of an environment for our conversations to take place. In his book, "The Physiology of Taste or Meditations on Transcendental Gastronomy" (translated by M.F.K. Fisher, 1985) he writes about the pleasures of the table. He describes how the family meal expanded. First, only the nearest

relatives were included, then neighbours and friends were included and later the tired traveler that brought stories from afar was included.

> Thus was born hospitality, with its rights sacred to all peoples, for one of the strongest of human laws is that which commands respect for all life of any man with whom one has shared bread and salt (p. 181).

He goes on to say that:

> It is during meals that language must have been born and perfected... The pleasure of the table are a reflective sensation which is born from the various circumstances of place, time, things, and people who make up the surroundings of the meal... The pleasure of the table are known only to the human race, they depend on careful preparations for the serving of the meal, on the choice of place, and on the thoughtful assembling of the guests (p. 181 - 182).

If my friends were asked what is important to me when I invite them to my home I am sure they would respond, the decorating of the table and laying out of a meal planned especially for them. In preparation for dinner guests, I plan weeks in advance. I attend carefully to the menu and who will be invited to sit at the table. This form of hospitality is central in my relationships with others. It is with this in mind that I entered the research process. I chose to show hospitality

to the research participants by partaking of meals with them. I could not imagine joining in conversation with the participants without a meal as the central focus.

Being hospitable to the participants has a greater meaning to me than just the sharing of bread and salt. Hospitality is not a common occurrence that people with developmental disabilities experience. Often their experience has been one of being pushed away and of not being welcomed. Society has created distance between those who are disabled and those that are not disabled. Schools have done this by educating children with disabilities in separate classrooms. Because of this I felt the need to be very sensitive to the creation of a hospitable and welcoming atmosphere.

Selection Of Participants

The careful attention I give to inviting guests to sit around my dinner table was considered in the selection of my research participants. I was thoughtful about who I would like to engage in dialogue with during the next few months. Hospitality was for me was more than just sharing of the meal. It included the desire to talk with others that were interested in reflecting on their lived experience.

I had invited two participants to sit and join me in reflective conversation. Their names are Percy and Herb. The participants and myself have a lot in common. In common we have our desire to develop our voices within the political community and to advocate for the rights of people with developmental disabilities. Percy and Herb are skilled "informants" (Lundy, 1982). They have both attended many conferences and workshops which focus on instructing the participants on how to advocate for the rights of individuals with developmental disabilities. Both Percy and Herb have been participants and presenters at these

conferneces. These experiences have helped both of them to name their lived experiences with ease.

I negotiated with the participants where the conversations would take place and traveled to where they resided to decrease the demand on them so that they could be active in our conversations. Either during the conversation or after the conversation we had a meal together in a restaurant that the participant selected. I was responsible for the cost of these meals. As equal partners we shaped when and where to meet, how long the conversation would be at each meeting, the questions to be asked, the questions that would not be answered and which experiences would and would not be shared.

Percy

I first met Percy in 1990 at a board meeting of the Alberta Association for Community Living (AACL). She was invited to speak as a guest on behalf of the People First Association, Edmonton. She had come before the members of the board to raise her concerns with the lack of inclusion of people with developmental disabilities on the AACL's board. She spoke with determination and honesty and with such insight that the board was silent after her presentation. This was the first of many meetings I would have with Percy before I asked her to participate in a research project with me.

In getting to know Percy I learned that she is a woman aged 32, she is a single parent with a daughter aged 12 and has lost a child previously. Her first daughter was removed from her and placed in the care of the government. While her child was in "protective custody," she died.

Percy herself had been placed in care as a young child. Her life was filled with despair and struggles. One striking experience for her was when she was

placed in a large institution for the mentally handicapped as a young school age child. The scare of this experience has continued to be evident in the telling of her story. Her home situation was filled with many foster homes until she lived with one family for over ten years. This is the one she calls home and this foster mother, her "mom".

She experienced many different school situations. Among these was a time of no schooling while living in the institution, but she also attended segregated schools for children with developmental disabilities or segregated classrooms in public schools. In spite of these experiences she went on to get her high school diploma at an adult vocational college. On completion of this education Percy became involved in the advocacy movement. In the past six years she has become one of the leaders locally, provincially and nationally in helping others understand the need to attend to the rights of individuals with developmental disabilities.

In November 1992, prior to my clearly formulating the research problem, Percy agreed to participate in the research. In March 1993, Percy participated in the first of four unstructured conversations that took place over the next four months. Each conversation was about two hours long. On the basis of our conversations an interpretative account of Percy's school experience was written. These interpretations were shared with Percy and further discussions with her have shaped the final presentation of Percy's telling of her lived story.

Herb

I first met Herb in 1989 at a conference. We both had attended to further develop our understanding of how to support people with developmental disabilities to advocate for their own rights. This was to be the pattern of our

meetings over the next three years. At conferences in another parts of the country I was to discover more about who Herb was as a man.

At 32, Herb is an articulate and quiet man. Afraid to offend others he is diplomatic throughout the telling of his experiences about what others have done to him about things beyond his control during his time in schools and in the community.

Herb is a member of a loving family from whom he continues to get support as an adult. His parents and siblings are very much part of his life. His dad has been helpful by supporting Herb in his activities as a provincial leader in the self advocacy movement.

As a child he attended school in many different districts because of his father's employment. As a family it was necessary to move almost every year. Throughout his schooling he attended school in regular classes, segregated classes, segregated schools and segregated work study programs. As an adult he attended adult vocational classes at a community college.

On graduation from an adult college Herb held many different jobs until he moved to the one he holds now as a van driver. He is responsibile for the transportion of employees around a company complex. Herb is particularly proud of this job, which he has held for six years, because he makes $11.00 an hour. He indicated often that he did not think many of his teachers would have thought he would be as successful as he has become. Although he is pleased with his accomplishments, he has often voiced his wish to be able to do other work. He has cited his limited education as the reason he has not been able to get other jobs. He is worried that other employment might entail the need for him to work with numbers and to spell, things he sees as his weaknesses.

Herb is a parent. He shares the parenting role with his girlfriend for their two year old daughter and his five year old stepson. Parenting comes easily to Herb. He is very loving and caring towards both of the children.

Along with his job as a driver and his work role as a parent, Herb juggles his volunteer work in advocating for himself and others who have developmental disabilities.

Herb's quiet manner of not blaming others made it difficult for me when I began to write about how he told his story. I had often felt disconnected from him as he told his story without emotion. When I would push him and ask why he was not more angry with the way he was treated in school, he would simply tell me that he understood what they were up against. The teachers were not to be blamed for they did not know any better. Herb was always calm as he told his story. He was different than Percy. I could identify with her more easily because she is like me, her emotions are closer to the surface. I felt a sense of injustice as I wrote Herb's story. His story always seemed so much quieter than Percy's, but on reflection, I have come to understand that his story reads this way because this is who Herb is, a quiet, unassuming, unselfish, noncritical man who was interested in telling his story, not in analyzing it.

Research Process

My research work involved working with Percy and Herb in a collaborative inquiry to tell their stories of their experiences in school. The specific task of the study was to allow both of them, as recipients of special education, to speak for themselves and to gain an understanding and insight into myself as a teacher while I interpret and make meaning of what was spoken.

Bogdan and Taylor (1982) explain the significance of studies such as this when they say,

> Research in mental retardation (sic) and institutions comes from people in powerful positions vis-a-vis the so-called retarded (sic). These views may not be lies, but they do not represent the whole story either. The stories of the powerless - the judged - add an important dimension to the study of mental retardation (sic) (p. 208).

At the beginning of the research Herb and Percy were given a copy of my proposal. They were assured confidentiality if they so desired on completion of the written work and they were informed about their right not to participate in the research, to drop out at any time, or to refuse to answer any question. Both have choosen to have their real names used in the thesis.

The conversations with Percy and Herb have helped me to gain a sense of the past from their points of view - an aspect often lacking in the written histories of schooling for individuals with developmental disabilities. Our conversations were narratives of Percy's and Herb's school experiences. Both willingly shared their uncertainties, problems and aspirations; I am grateful for this. I have come to know their thoughts and feelings. I have come to appreciate and care for each of my new friends. Our conversations have enhanced our connections with each other. Our repeated conversations have helped me to find threads of my life, threads upon which I have been able to reflect . Pieces of Herb's and Percy's stories are, and will continue to be given back to me through my teaching.

Our talks seemed undirected at first. Later, the transcripts became our road maps to refer to as we planned further conversations. They provided the skeleton for burrowing deeper into the experiences within each moment. For me each conversation was much like going back to a previously visited place and exploring the area further. The return had feelings of familiarity but presented new experiences. Even though I could return to the transcripts to guide our next conversation it was hard to know what each subsequent conversation would entail for it was not yet part of my body; I had not yet lived through the writing of Percy's and Herb's story.

I spent very little time with the conversation transcripts of meetings with Percy and Herb in the beginning. Then, as time went on, I spent more and more time with them. I turned their words over and over as I discovered the richness inside them. I explored their words with excitement and pleasure for they shaped my sense of their stories.

With each participant I had four taped conversations. The conversations ranged between one and one half to two hours long. After each conversation I would transcribe our conversation. Before the next meeting each participant was given a copy of the transcripts from the pervious conversations. Rather than use the transcripts to guide the next conversations we decided that we would talk and allow each discussion to guide us on reflecting upon their school experiences.

What Is A Research Relationship?

I believe that in using a methodology of intensive conversations, it is not possible to take the data and run. The methodology I have chosen has forced me to consider how relationships may develop beyond the research. I have had

to consider my role in the relationship as it goes beyond the research process and how it extends to involve the needs of my participants' topic.

As the research progressed, the building of a positive rapport and a strong sense of mutual support between myself and the participants became apparent. This rapport came about because of the many conversations necessary to collect the data as well as the emotional topics of the conversations.

Narrative inquiry as a methodology requires the development of rapport with the participants. Face-to-face extensive conversations with people lead to relationships with participants that are characterized by openness and trust. Good narrative inquiry inevitably involves the creation and cultivation of relationships. In the research, the relationships have taken many forms. However, at the core of the relationship there was a measure of personal care and respect.

The type of relationships that have formed during the research has made me feel awkward and uncomfortable at the end of the research. I have been concerned that my participants might feel used as I begin to "ease out" of the research relationship (Taylor, 1991). When I first withdrew from our intensive conversations, I felt a sense of loss on the part of my research participants. Both represented this feeling to me in different ways. One participant, in a telephone conversation, suggested that we get together for coffee. The other participant, in a phone conversation, had difficulty allowing our conversation to come to an end.

While I reflected on and interpreted our conversations I maintained contact with my research participants for two reasons. The first was that I had come to know both of them better and was enjoying my increased contact with them. This was maintained through my volunteer work with the "People First" movement. The other was that I wished to have the research participants confirm my

interpretations and to enable me to gain further understanding of their school experience.

On the completion of my research with Percy and Herb I find it difficult to put parameters on my relationships with them. I cannot see myself cutting off all contact with them, because I enjoy both of their company. Gallmeier (1991) suggests that "(t)he process of disengaging from field settings is as important as the process of gaining entry" (p. 230). Stebbins argues that "(s)emistructured interviews ... tend towards the development of interpersonal relationships as the interviews unfold" (p. 250). While Taylor (1991) asserts that,

> ... when we cultivate close personal relationships with informants, we sometimes incur an ongoing responsibility to them. Many informants neither want or need to continue a relationship with us and at best tolerate us while we are conducting our research. However, some of the people we study are vulnerable and lonely and come to depend on us. A common problem among researchers studying people with mental retardation (sic) is that they become their subjects' best and only friend. This has happened with three of my doctoral students. Whether by phasing out of the relationship gradually, helping the person to find other friends, or staying in touch it seems that we owe something to people whom we have encouraged to become close to us (p. 246).

When I began the research we were acquaintances. When it ended, we had developed a personal relationship. Our friendship rested substantially on our

shared interest in advocating for the rights of individuals labeled developmentally disabled. My participants have helped me gain a better understanding of the "People First" movement even though this was not the primary focus of our work together. Having conversations with two individuals whose enthusiasm about advocacy is similar to mine brought us closer together as kindred spirits. This contact is what Stebbins (1991) calls "structured contact". We continue to be brought together through our advocacy work which provides the frame for our further relationship.

Interpretation And Representation

Kirby & McKenna (1989) suggest that the researcher's task is to bring the data together to "make sense" of their life experience.

As I struggled to represent the stories of the two participants, I was struck by the importance of representing the work to make it available to more than the research community. My participants reminded me often that the work must not be a specialized activity for a select few but rather one that speaks as well to self advocates and teachers. Kirby & McKenna (1989) remind the researcher that when working with those on the margins one must "maintain a focus on the world from the standpoint of the margins, to openly recognize the experience of marginalization and to use it as a touchstone" (p. 65). The Webster's Dictionary defines touchstone as "any test or criterion for determining genuineness; the touchstone of common honesty". In my research I have attempted to remain sensitive to the fact that the possibility exists for misunderstanding, stereotyping and misrepresenting my participants' experiences. In the collection and interpretation of the data I have worked under the assumption that people experience the world differently and, because of this, people have different

knowledge. Representing knowledge of the participants was the intent of the research. I view their knowledge as valuable and of great importance in shaping my understanding of how individuals labeled developmentally disabled experience school. As a friend once said, "When someone shares their story, you have responsibility for it" (Sewall, I.,1992). I feel I have a responsibility to represent the participants' stories with the dignity that they deserves. I have a further responsibiility, that is, to carry it with me forever.

Interpretive Process

I began the interpretation by transcribing the tapes so that I could read the transcripts to locate the conversation threads. I read the transcripts for themes within each participants' story. I then reflected on the common themes, given my interpretation of the participants' experience and wrote the main themes I interpreted in each of the participants' stories.

The participants' then were given copies of the written interpretations. For Herb I read the chapter while for Percy I left them for her to read. After the participants became familiar with my interpretations, they were asked to respond to the accuracy of their tellings. They were encouraged to state if they did or did not represent their own interpretations of the situation. We then negotiated how the documents should be changed to reflect their interpretations of the situation.

Writing The Story

I approached the task of interpretion of Percy's and Herb's words with caution; I wanted to treat their words with dignity. The desire to do this made me

feel paralyzed at times for I feared I would not share their thoughts in a way they would feel represented.

In my struggle to determine how to present Percy's and Herb's stories, I felt a sense of loneliness. I no longer was in conversation but now was charged with having to write an interpretive account of their stories. In my desire to understand this loneliness, my mind often returned to the images of our conversations. My mind teemed with images of sitting side by side and face to face with Percy and Herb. I wanted to reach out in my writing and reconnect with my participants and maintain the sense of connection in the written account of our conversations. I wanted the reader to experience the interpersonal communication between myself as researcher and Percy and Herb as participant. To accomplish this I have chosen to write the next two chapters to my participants as an extension of our shared conversations.

In planning and preparing for the writing of this thesis, I spent a lot of time reading what other writers and researchers said. As I wrote of Percy's and Herb's lived experience and my interpretation of their words, my readings reminded me of Percy's and Herb's words and my reflections on these words. I have chosen to represent the words of other authors in a different format so as to set them apart from the participants' words and my reflections on their words.

In the next two chapters you will meet two people who have, at one point in their lives, been labeled developmentally disabled and have experienced schooling in a regular class, a segregated class and a segregated school. I welcome you to read Percy's and Herb's stories.

CHAPTER THREE

Percy

Beginning The Conversation

> *Don't stop at the tears; go through to truth* (Goldberg, 1986, p.10).

When I began working with you, Percy, I felt the desire to stop at the tears. I did not want you to experience the pain again through the telling of your school story.

> I'll start off with segregation in terms of being in the educational system. It has been very devastating spiritually. To grow spiritually, confidently wise and have a voice. Even as I talk I can feel the emotions arise (conversation transcripts).

As I reflected on the transcripts of our first conversation , I realized I was preventing you from going on to the truth. I needed to encourage myself to support you through the tears so that we could, *"...come out the other side and not be thrown off by the emotion"* (Goldberg, 1986, p. 10). I had to force myself to be open and trust in the process; to be open in the face of tremendous opposition; to be open to hear your voice as you peeled away the layers of your heart. The mixing of tears and pain in your voice are as much reflective of your lived story as were the words you used to name the pain. As I listened I had to

allow your words to go deeper and deeper inside me so that I could use your rich words to understand.

Loude (1984) suggests that there is a distinction between pain and suffering. For her, *"pain is an experience that must be recognized, named and then used in order for the experience to change, to be transformed into something else, strength or knowledge of action"* (p.172). Living through pain that has not been recognized and named deprives a person from using the power to move beyond the point.

As I listen to the pain in your voice, I had to remind myself that you had lived through the pain and had survived. I heard in your story how you used this pain to strengthen yourself and be transformed into the woman you are today.

> I swore I would never be put in this position ever again and I would fight. Because some how I knew it wasn't right. Because I would see how the others were being treated. We were different. As I got older I started hearing about human rights. ... I was always the underdog. ...I kept dreaming so long ago that I don't always want to be this way. Then as I got older the dream kept coming closer and closer. ..I eventually said I am going back to school. I wanted my education so badly. ... This is why I am smiling because I got my grade 12. I was integrated and I was smart. I did it (conversation transcripts).

Who Should We Blame?

When one knows the name it brings us closer to the ground. Percy, you make me feel this way in the telling of your story. You have gained the names of the actions around you; you have become stronger in your ability to face the oppressive stance. It has helped to take the blur from your mind; it has connected you to the truth of the situation. In naming the pain and suffering you experienced you placed the blame for your segregated education in the hands of the bureaucrats.

> I have to leave my anger with the bureaucrats because they are the ones that are the decision policy-making people. In terms when I was younger I was very angry at instructors because of the impact and the way I was treated when I was younger. I didn't understand. It was a kid, child's point of view. And years ago, yes, I was angry at the teachers because you know in a kid's mind that is what you see. You resent the person that is teaching you because you are not being heard. And today I'm not angry with the teachers because I can see it really lies with the bureaucrats (conversation transcripts).

As an adult, you have come to believe that the blame should lie with the policy-makers for your education in a segregated classroom. For you, it is the bureaucrats that set policy that will decide how children will be educated.

Policies of the time and still today (Uditsky, 1993) *were developed without addressing or confronting the school districts' historical practices and*

assumptions about students with developmental disabilities. The education policies for students with developmental disabilities usually rest upon assumptions which are wrongly presented by policy makers as sociological truths.

Skrtic (1991) *says the prevailing assumptions about disabilities and special education are that disabilities are human pathologies; diagnosis is objective and useful; and special education is a rational system that serves diagnosed students.* Hahn (1989) *states that research in special education has been focused on a "functional limitation" model which supposes that the disability resides in the individual and the solution to the disability is to transcend these deficits to the maximum extent possible.*

When you were a student, Percy, the internal deficit model was central in the policy-making.

Diminished Expectations

> I wanted to learn to drive a car for example when I was fourteen because my brother started showing me. We were put into a class in the regional high school. I remember very vividly what happened. We were told we would be taught cooking and that we would be taught how to do things like laundry. Things for everyday life. That was fine. This class was specially called the EMR room which was the Experience Mastery Room. The goal was for the instructors to teach everyday living skills. Then she asked us what do you people want to learn? I said, " I would like to learn how to drive. My brother is teaching me. I don't mind learning to

> cook. I already started to learn how to cook. That's what I want to do." The teacher said, "No! You don't drive a car. You are too young to drive a car." That is not appropriate Percy because that is not everyday living (conversation transcripts).

Percy, while you believed in your own capacity to learn, others did not always share this view. When you expressed desire to learn something you were told through words or actions that you had to learn what others wanted you to learn.

> Again all the decisions were made without asking you or anybody else in that situation. We never were given an opportunity too. It was always that the teacher knew best (conversation transcripts).

Your educational experience was filled with lowered expectations. You often wondered why you were not expected to meet the norms of performances set for students without a disability. In the telling of your story you have been able to provide a wealth of illustrations of inappropriate accommodation to your educational needs.

> ... I never learned anything in New Hope. I remember learning how to wash dishes. ... They took us on a lot of field trips. I remember that but they didn't teach us really anything about history, mathematics. ... It was when we were suppose to learn social studies it was again Mickey Mouse

> stuff. She went as far as to describe the St. Paul area. I said to a friend, "Why don't we learn the cities and capitals like other students"? ... Math and Language was modified and if they did call it social studies it was basically Mickey Mouse stuff (conversation transcripts).

Lipsky and Gartner (1989) found, *"Unanimously, disabled students and parents of students in every educational setting complain that adapting and accommodating to disability all too often resulted in lowered expectations and patronization"* (p. 184).

Your experience unfortunately is a common one for students with developmental disabilities. During your educational career I sense you did not meet teachers that were committed to minimizing or limiting the practice of diminished expectations and making adaptation without patronizing you as a student. You repeatedly encountered individuals whose attitudinal barriers limited your access to education.

What Is In A Name?

> ... This class was specially called the EMR room which was the Experience Mastery Room ... (conversation transcripts).

The class label "EMR" is a symbolic act that shrieks like a siren to me while alerting me to the attitudinal barriers that you might have encountered. At the time you were in school the label "EMR" was very salient and powerful. This label, for me, speaks of diminished expectations for it says "the students in this

room have a developmental disability." As a teacher the label "EMR" means "Educable Mental Retardation".

Allport (1954) states, *"The very act of classifying forces us to overlook all other features, many of which might offer a sounder basis than the rubic we select"* (p. 178). The label "EMR" given to the students in your class refers only to one aspect of their nature and does not correctly refer to their whole person. *However, the chances are that the label "EMR" stood out to others as the "primacy potency"* (Allport, 1954).

What does it mean when the label "EMR" is absent of the truth of what it stands for? What are we doing when we can't say what it really means out loud? What was the cover story? Did the educators believe if they coded the word there would not be the effects of the label on the students? Did they understand *"... in the cultural trade of labels "retarded" brings negative value. In everyday parlance it is a pejorative as well as a psychological term"* (Biklin, 1992, p.12). Did they choose not to say what it really meant in an attempt to prevent this attitude from happening? *Did they believe that they would be able to prevent the stigmatization* (Goffman, 1963) *the label "retarded" brought upon the individual?* When the educators chose to call the class "Experience Mastery Room" had they forgotten how a number of essential factors influence teacher's expectations of students.

> *... teacher expectations are influenced by the specific pedagogical theories and conceptual frameworks, as well as educational structures and practices, instilled by teacher training programs. This category reflects the climate of expectations surrounding testing, tracking and record-keeping* (Darder, 1991, p. 17).

Educators may have believed in the imaginative practice that if we do not say out loud what the label means maybe the ill effects of labeling will not affect the students in this class. The coded label did not prevent you from experiencing the ill effects of labels. This coded label did not distract your teacher's attention from the concrete reality that you were placed in a class where lowered expectations were part of the culture.

> Then someone else said, "I want to learn science." Other people said we want this and we want that. Some of the things she agreed with. The ones only she wanted. What she thought best for us (conversation transcripts).

Membership

> Even as young as I was I knew that it was segregation. I would see all the other children go into the other school. That feeling of isolation was reinforced. ... Segregation, people don't realize that it does a lot to you (conversation transcripts).

Webster defines membership as *"the state of being, or status as a member"* and with membership comes privileges and relationships. O'Brien & Lyle O'Brien 1991 point out *"... knowledge of our membership in each other lies beneath words, in everyday habits"* (p. 1). People experience many forms of membership in schools; we speak of membership in a class, in a school or in a club. Membership lies in a feeling of belonging, being part of something. This belonging generally is related to relationships with others.

Percy, in the telling of your story membership was not something you felt while in school. Some may argue that you had membership within the classes with your peers with disabilities. However, this was not the form of membership you valued. The membership you wished for was to be "one of," not "other".

> At the odd time and the schedule had to be rescheduled we would sometimes end up having recess at the same time. We would see the other kids and I remember standing by the wall and wishing that I could be over there (conversation transcripts).

"People spontaneously acknowledge membership in culture, neighborhood, association, and family through signs and rituals that signal belonging and set boundaries" (O'Brien & Lyle O'Brien, 1991, p. 1). The boundaries were set for you by the curriculum and the setting in which you were educated.

> ..it goes back to having no value. We weren't part of the regular curriculum... The teachers were treating me like I don't have a mind or they would give me simple stuff. They would leave me in the corner and a lot of time I remembered looking at a paper. I was so full of emotions I couldn't think straight. I wasn't taught to like think logically. So sometimes I would just stand and stare at that paper. I wouldn't do nothing ..... It was so helpless because again they wouldn't explain, they would just say read the instructions. (conversation transcripts).

Your sense of isolation brings me back to you laying the blame with the bureaucrats who set the policy. O'Brien & Lyle O'Brien (1991) *speak about those in charge and their charges being discouraged from knowing each other as members of one and another. When this is promoted the sense of being put aside arises from the unthinking denial of membership. The setting permits the moral exclusion of people. "[The] denial of membership decreases people's power to pursue their goals and increase their vulnerability to dehumanizing or neglectful or abusive treatment"* (p. 6). Your own words speak to what O'Brien & Lyle O'Brien have raised.

> I use to sit there quietly and the odd time I would risk things like go run to the other school. I didn't have the confidence to talk back. I obeyed like a meek little dog. Also obedience was beaten into you. I felt that way (conversation transcripts).

Throughout our conversations the idea of feeling cast aside was in and beneath your words.

> I saw that segregation ... we were set aside and I felt ... in terms of my being segregated that we were different and that has stayed with me forever..... (conversation transcripts).

Your words touched upon your feeling of being excluded. However, for me your voice told more than your words. I find it hard to find words to adequately match the feelings that you felt about being excluded. I wonder if the poverty of

words are because it is hard for me to imagine what it must have been like to experience such long term pervasive exclusion.

> When I was a kid I didn't know that we were being segregated, I just knew that we were apart. I just felt it. I don't have the right to be in this school. It was said very strong by the way teachers treated us... What I mean by this is oh you do this now. Thinking for me. Telling me how to do things, not allowing me to think for myself and expand my mind. We were talked at. Everything was done for us ... I hated being told what to do. Not being allowed to think for myself. Having my input, you know, child input. I always stayed in my bleak little world. I showed no interest. I didn't show no interest because it was so deeply rooted in me. It was said over and over verbally, sometimes they would come out and say that you are mentally retarded and other times they would do it in a round about way but still you hear the message. So I got to the point that I didn't care about school. I hated school with a passion. I still feel sad now because it still hurts even today as an adult. I can remember thinking to myself am I ever going to get out of this (conversation transcripts).

I wonder if the lack of words to describe your sense of isolation and rejection reflect our cultural devaluation of relationships (Gilligan, 1982). *In our western culture we celebrate the characteristics of autonomy, individualization, separation and natural rights over relationships and connections with people.*

Compounded by the devaluation of relationships in our culture and lack of ways to describe such relationships your experience reflects how people labeled developmentally disabled are placed in deviant social roles (Taylor & Bogdan, 1989). In other words society's rejection of and exclusion of people with a developmental disability denies them access to relationships with others, something that was predominate in your school experience.

You went on to describe some of the consequences you see as part the long term exclusion from regular school membership.

> I felt when I was in a segregated classroom my social skills were affected because I was never taught group interactions, one-to-one interaction. I didn't know. It was that bad. I didn't even know how to cross the street. That's how bad they had control on me because things were always done for me. The teacher always did it for me and when I came face-to-face with it I didn't know what to do with it. I was too scared to trust my own judgment because that's what segregation did. It took my own belief away (conversation transcripts).

You dealt with this sense of isolation and denial of voice by withdrawing. This added to your sense of being sucked into a black hole from which you saw no escape.

> I was in a black hole... It created a lot of insecurity... the way the teacher treated me. I was less worthy. I was really frustrated. I know I remember thinking I don't want to go to

> school anymore. The bottom line is that people shouldn't ever be treated like that (conversation transcripts).

Although you have been able to understand why you feel the way you do about your segregated education you are still hurt by its affect on your emotional being.

> I still feel sad now because it still hurts even today as an adult (conversation transcripts).

Losses

The devastation of segregated education and the losses you experience because of it are a major theme for you. You described the effects of segregation on your life and your feelings about these effects and in your telling you encapsulated the complex effects of segregated education. Your feelings of devastation are based on your remembered images.

> There was an instructor in the classroom where I wanted to ask a question but at the time I was a very nervous and insecure child and it didn't come out right because it sounded funny to them. The teacher laughed at me. Literally said, "She's retarded. Don't listen to her." That really hurt (conversation transcripts).

In your account there is a strong oppressive aspect exerted by those in positions of authority. It is not surprising that this oppression surfaced as inner

frustration and despair. You articulated despair and frustration with the oppression you experienced in school. This despair revolved around the control and enforced dependency imposed on you in school. The constraints placed on you by teachers is related to the assumptions educators may have about people with disabilities. As a student you were viewed as dependent, passive and unable to learn.

> It was recess time and I wanted to go and talk to the instructor. I overheard that instructor saying to the other teachers, "Well we've got to program things for them. They can't think for themselves." I really felt devastated. That's when I went home and told my mother that I wanted to kill myself because that's how bad it was for me (conversation transcripts).

Often in our conversation I sensed how painful these experiences were for you.

> ...It goes back to not having no value. We weren't part of the regular curriculum.... I felt like a burden.... It all goes back to you are a number. I can't describe it...segregation, people don't realize that it does a lot to you. I just felt like a nobody (conversational transcripts).

Voiceless : Powerless

A recurring theme in your story was your need to be heard, to have a voice, and to have a sense of belonging. *"It is important to find a voice in order to find a place"* (Hogan & Flather, 1993, p. 105). You lacked a place in which you felt comfortable during your school years. You were trapped in a silence with little hope of escaping. You were waiting to be invited in; you waited behind a "wall of silence" that you were forced to construct.

In school you were not given the opportunity to construct your own story. The story that you lived was constructed by educators, adults and society in general. You were denied a voice while others constructed a story that did not reflect your dreams, hopes and aspirations.

> Well everything pointed to, we were never given room to talk. We were never valued. We were always treated disrespectful. We were pushed into programs never asked. We were never given praise. It was always criticism. You didn't dare ask questions. ... For the longest time I thought I had to bare this cross. I was being punished (conversation transcripts).

In addition to feeling you had no worth, you felt in some way responsible for the treatment inflicted upon you. You took the blame for your situation upon yourself. As Allport (1954) states, *"The primary reason is that in our western culture we hold the doctrine of individual responsibility. It is the individual that shapes his world, or so we believe. When things go wrong the individual is to*

blame" (p. 151). You were shaped to regard yourself as responsible by the system of domination and the cultural norms around you.

You experienced pain as a result of the dehumanizing, oppressive forces you encountered. These forces appeared to render you invisible and denied you the recognition you desired. You had little hope of acquiring a public voice. There was no vehicle to enable you to articulate your pain. There was no public discourse or audience to give your pain a hearing.

> We were dummies to them. We were not suppose to think. It goes back, to I am the professional. You are not supposed to make a peep. I'm not capable, I wasn't capable to them and many others (conversation transcripts).

As a student you felt powerlessness. You were not seen as having a part in the construction of your learning. Knowledge was to come from the outside. You were seen as not being capable of constructing your own knowledge. Blind obedience was valued over self initiation and thinking for oneself. It is not surprising that in order to deal with the denial of your voice and feelings, you felt you needed to develop a wall around yourself. It was necessary for you to survive by hiding your true feelings.

> I never liked school when I was younger. I did poor. I always had poor marks in school. I was forever failing subjects. I didn't care about school because of all these feelings. I didn't know how to deal with them. I would just build a wall around me. I went only because I had to go. I had no voice. I was just a thing (conversation transcripts).

For you there was no sense of mutual choice and negotiation. The professionals were those in power and viewed people labeled developmentally disabled as not being capable of speaking for themselves. You had no sense of liberation. You were on the outside. You experienced the authority around you as all-powerful.

> I never had no sense of input, no value, no purpose. Like now I am an adult I think back that they should have shared the purpose and why. They don't have to use big words. They should encourage the kids that have talents. Like if they can sing or draw. Like Crystal (my daughter) draws. She picked that up from me. Kids should be heard for themselves whether they are integrated or not. The parents and teachers need to work together more. They stress the emphasis that they need to coordinate this because this is a better program. I still hear that from Crystal's teacher. He sets up the times and I still see that the program is set up and we make suggestions. If he is for it, okay but if he is not, look out.

Your withdrawn and passive manner slowly began to change. You began to speak out. As you told your story, in the beginning stages your voice was angry.

> I was scared. I wouldn't go to the teachers. I remember being in the special ed. I was slowly integrated at that time.

> That was when I started to say to teachers I don't like this and I don't like that. But I would come across in an angry way. I didn't know the other way (conversation transcript).

As you initially developed a sense of your own voice, you found that your voice was filled with anger. You began to question the authority around you. Were you aware of the risks of questioning it? Is this why you remained silent when you knew you wanted to speak out against the oppression you felt?

> I am starting to feel anger again in me. I remember feeling angry when I was in school. I always kept it in me. The only difference now is that I express it. Back then I held it in. ... I remember drawing mountains and birds with faces on them. That was my way of saying I want freedom but I couldn't say it back then (conversation transcripts).

During your years in school you were forced to believe that it was necessary to obey authority. The overpowering sense of this authority rendered you silent. In reflection, this angers you as you now know how to respond and deal with your earlier need to survive through blind obedience to authority.

Storyless

Your experience of doing poorly in school reflects the notion of self-fulfilling prophecy. What people thought about you was bound to fashion what you did. You were given the message of not being able in countless subtle and not so subtle ways. Your teachers viewed you as unable so their actions

provoked such a response from you. Your dislike of school and failure reflects your response to your teachers notions of your lack of ability.

> I noticed when I was in school I had no motivation. No sense of direction. It was just like I was in a world that I was just a robot. Just doing things. ... I remember this teacher in particular. She told me, "What are you going to do when you grow up?" And I said I don't know. ... I was too scared to say what I wanted. So she got angry.

Getting A Story: Journey Into Adulthood

Getting an education had always been a dream for you. No matter how devastating your life became at times you never let this dream disappear. In telling this part of your story, your voice began to carry with it a strength that I did not hear when you spoke about your public school days.

> Eventually I said, "I am going back to school." I wanted an education so badly. I went and inquired at Alberta Vocational College (AVC). I went through the interviews by myself and the testing. I tested at that time at a grade six level. ... I did my testing. It took three years and now I have my grade 12 (conversation transcripts).

Your story of your early days in school did not have the sense of strength and self determination that this part of your story did. In telling this part, it was the first time I heard you speak of having fun and just enjoying yourself. You still

encountered difficulties. However, you did not feel helpless to change your situation.

> Those three years were okay. I made friends. We had a ball sometimes. I had some problems with communication with some instructors. But I think that goes along with any place that you go. I would say that. This is where I am smiling because I got me grade 12. I was integrated and I am smart. I did it. It took a while. I even had at AVC two particular instructors, because at that time I still had low self esteem. Sometimes I would go into myself so deep like the old behavior that they thought I was slow and that I would never get my grade twelve. The counselor wanted to put me into another course. Well she did. I said, "Okay, I'll do it just to prove to you that I can do it, but then I want my 23. I want to get my English 33." I said that was the only way I will take that Mickey Mouse course because to me it was a Mickey Mouse course (conversation transcripts).

To accomplish what you set out to do, to get your high school diploma, was not easy. You still needed to convince others that despite the label placed on you, you were determined and able to accomplish your goal.

> So I did that fine and finished it. Okay now I want my 23. they hemmed. I said, "I want my 23." And that is when I started to notice that I could speak out because that is what I wanted and I wasn't going to back out. I can remember

> standing there with my hands on hips saying, "I want my 23 and I am going to get it." But it was a dream I always wanted. I wanted to prove to others that I'm not stupid. I have disabilities that stop me from doing things but there is nothing wrong with my mind. Except at times when I get nervous and insecure I will say things backwards (conversation transcripts).

This sense of accomplishment helped you to begin to stand up for yourself and question the traditional views of what was best for students labeled developmental disabled. You saw yourself as an example for others. You began to share your doubts about traditional education and began to question if segregation was the right way to educate children who have been labeled developmentally disabled.

> My (foster) mother never really understood and still doesn't even today that I was integrated and that now that I am finished my school, she still thinks the old way that some of them need to be institutions and in segregation. I told her, I didn't get angry, I disagree with you because I'm living proof and look what it did to my self esteem. I couldn't communicate like I know today. Then she said, "I don't know, maybe you are right." ... I said to her "That it was lucky that I had the determination and I learnt those skills but some of them don't have the confidence" (conversation transcripts).

Sharing The Success

You contributed some of your success in maintaining your drive to complete your high school to a teacher who was supportive of you when you were a student in the adult education program. This teacher was someone who had given you strength.

> She was good. She saw my skills and said that you're going to go a long way and you're going to be a leader. Back then I laughed at her and said, "No." She said, "Yeah I see it in you. You're getting stronger everyday" ... At the time I still had problems. She would say "Listen to yourself. You know what it takes to be a leader. You just have to build yourself up and you will be there. Some day you will be phoning me and saying you've done it" (conversation transcripts).

You valued the support from this teacher. She was supportive to you in many ways and you carry fond memories of her. You still feel connected to her. The fact that you contacted her to update her on your successes is reflective of this.

> I did phone her the other day. I told her I am now a president. I sit on the executive of a provincial association and I was a board member prior to that for one year. I sit on these committees and I speak. She said I knew it. So I guess in terms she kind of gave me the confidence (conversation transcripts).

As a teacher I feel one of the greatest compliments I can receive is to have a student I taught tell me how instrumental I was in his/her life. Taking the time to contact your past teacher is testimony of how important she was to you.

Your interest in sharing your success goes beyond sharing with this interested teacher. You have, and hope to continue, to touch base with other teachers who taught you. Your purpose for this contact has been to share the fact that you have been successful in securing your high school diploma.

> That principal I showed him my certificate and he was shocked. I like pulling that trick. I get a kick out of it (conversation transcripts).

When I asked you if you had tracked down a specific special education teacher you had, your reply was;

> I would like to see her. I will have to back track. I did that once with a board member. I was trying to back track a teacher, someone from New Hope. This woman she sits on the board. ... I said have you found my old school picture yet? Will you be able to tell me where Mrs. _____. is? She said she is somewhere here in Edmonton. I told her that I would like to go and talk to her. I didn't tell her why (conversation transcripts).

The sharing of your success has been an important marker in your life; this has been especially true for people who doubted you.

Percy, completing grade twelve reflects your resistance to the power and plot expectations set out for you as a person labeled developmentally disabled. You have demonstrated *"identity is a construct, not a fixed reality"* (Frye, 1986, p. 47)

Advocacy

> I started within the school (AVC) itself. Because I saw a friend of mine that watches Crystal (my daughter). She was being shunned. So I went with her to the president for each area of the school. So we went and we took a bunch of us students. I went and had the courage to tell this Agnes (a teacher) off, Agnes wouldn't listen. They were going to start expelling me from programs. I said you can't do that; I haven't done nothing wrong. My marks are up. I didn't know I would go with Joyce (my friend) and talk and eventually she would get to finish the program. It took hours of coffee and it took talking to other students. I guess I was always determined. One counselor told me even at a young age people labeled you as angry and feisty. That is because you had a will. A strong will. They interpreted it as a problem behavior.

This experience gave you the confidence to speak up for yourself and for others who are being oppressed. From this experience you have begun to feel that you could advocate for yourself and others.

In our relationship outside of the research you helped me see that advocacy is what matters to you, advocacy is what makes you feel real,

advocacy is a way of expressing yourself more freely and of being known. Advocacy work has helped you find ways of expressing much of what had been unspoken as an child. Your path of resistance took the form of political awareness (Kim, 1991).

Conclusion

Percy, although it is a painful reality, you have not been afraid to look at your school experiences. Your school story is filled with painful images. Hearing your story has allowed me to discover a clearer image of how children with developmental disabilities might experience segregated education. As bell hooks says in her work on discrimination and black people, *"It should hurt our eyes to see racial genocide perpetuated ... "* (1992, p. 6). Listening to the your experience should be painful, for that is the reality of your school experience. Your words are a powerful testimony about some of the experiences persons with a developmental disability have and might experience in school.

Your past experiences have given you an insight into your present experiences (Clandinin, 1986). The telling and retelling of your childhood story has contributed to the strength I now hear in your voice. *"When you can speak of something, name something, laugh at something, you show your control over it."* (Barreca, 1991, p.169). I hear in your voice how you have worked out some of the important ideas related to the nature of your voice and empowerment. To grow you needed to have a sense of your own personal power and voice.

Percy, you have shown me that *"...you can go through to the other side and actually come out singing. You might cry a little before the singing, but that is okay"* (Goldberg, 1986, p. 103). Percy, you certainly are, in spite of your disability, a woman of extraordinary resources.

CHAPTER FOUR

Herb

Beginning The Conversation

Our conversation started late one night as we sat on the floor in a hospitality suite in St. John's, Newfoundland. Like always our paths crossed at conferences and board meetings. This evening was no different than many others we spent talking with each other. On that night I told you I was attending university and was interested in inclusive education for all children. In response you began to tell me your school experience. The openness and trust with which you shared your school story that night made me keenly aware of your deep desire to have others hear your school story . On reflection, this conversation shaped the focus of my thesis work. You alerted me to how your voice had not been included in my understanding of how to welcome all children to their neighbourhood schools. While listening to you I realized I needed to hear the voices of individuals who had been labeled and segregated. This would be necessary to further shape my understanding of my role as a teacher in the education of children with developmental disabilities.

Your Story: In The Beginning

I hear the question over and over in your narrative, "Why didn't my grade one teacher care enough to help me learn?" (conversation transcripts). Your story begins as you told of your grade one teacher who allowed you to colour rather than to attend to the lessons being taught.

> To tell you the truth, I am blaming her for all my education that I never got. ... Where was she when I needed her?... You were the teacher. Why didn't you teach me? (conversation transcripts)

You are puzzled by this because your memory of your grade one teacher is that she was strict and expected children to attend.

> I know she was a strong person because she always was strict. Like if you deserved the stick, you got the stick (conversation transcripts).

Why were you not expected to "attend"? Why did she single you out with different expectations? What was she thinking when she let you colour each time you encountered trouble with the concept being taught? Why didn't she expect you to try? Why didn't she take the time to help you understand? These questions are at the base of our discussion and trouble you because they can not be answered.

As a teacher, I wonder if your grade one teacher struggled, as many do, with believing she must balance the complexities of numbers and diversity of the children in her class. This belief often becomes a focus because, *"... teacher(s) feel, and (are) made to feel, that one's worth as a teacher will be judged by how much a class learns in a given time"* (Sarason, 1982, p. 187). Sarason states that

> *".. by and large, teachers accept this state of affairs. They may criticize the amount of material they are expected to*

cover, they may feel badly that in the process certain children fall by the wayside, and they may bitterly resent that their worth as teachers is judged primarily by the average achievement level of their class, but they do not question that a time criterion is necessary" (p. 188).

This view of children being able to move through a "lock-step" set of curriculum in a certain time period may have been at the foundation of your school experience. This approach makes assumptions about the ability and performance of children of similar age. Your teacher may have been influenced by this rigid view of teachers' responsibilities and you became the child who fell to the wayside.

What Grade Were You In?

In telling your school story you followed a chronological order. You received your education in a number of school districts. This was because your family moved a number of times due to your father's work. The following was compiled from our conversation transcripts:

Year 1: Grade one regular class --- Derwin
Year 2: Grade one regular class but didn't finish year out here--- Derwin
Year 2: Grade one finished in Calgary --- Calgary
Year 3: Grade two regular class --- Calgary
Year 4: Special education class --- Airdrie
Year 5: Special education class --- Airdrie
Year 6: Special education class --- Airdrie
Year 7: Grade five regular class ---- Rockyford

Year 8: Regular grade six class part of the year then transferred to special education at a different school --- Calgary
Year 9: Special education class --- Calgary
Year 10: Grade six beginning then transferred to a segregated School in the middle of the year---- Drumheller
Year 11: Vocational Transitional Program --- Drumheller
Year 12: Vocational Transition Program --- Drumheller

I have used the marker of year in school rather than the grade because what struck me in your narrative was your difficulty in clearly stating what grade you were in. You had no difficulty remembering schools and teachers' names. However, when asked, "What grade were you in?", you would pause and struggle to give a response. You put great effort in trying to place a grade marker on your school experience but were not always satisfied with your response.

> When I was in special education in Calgary I was back at a lower level. Every time I was put in special education there was no grade, just a lower level. So I got confused. When you do the same work over and over you kind of lose track of what grade you actually have taken. When I was going to school it was plus and minus. That is all they figured I could learn. I never learned anything until I went to TVP (Transitional Vocational Program), the work study program (conversation transcripts).

The movement between school districts and regular and special education classes added to the confusion. I sensed a lack of rhythm as you told your school story. Connelly and Clandinin (1988) suggest that, *"(r)hythm is an*

expression of some part of the narrative unity arising out of our past and embedded in our cultural and historical narratives and the institutions in which we are a part" (p. 76). Trying to view school grades as markers of your storys' chapters has made it difficult to follow the plot of your story. The chapters are not clearly defined. Each school district met your educational needs differently. Some school districts placed you with or without your age peers in regular classes, while others placed you in special education classes and still another moved you to a segregated school.

This lack of rhythm is reflected in your struggle to describe what grades you were in. Your school story seems to lack a beginning, a middle and an ending. There is no link between the chapters. The only time you seemed to be able to confidently say what grade you were in was when you returned to a regular class. Being in a "regular" grade clearly assisted you to state what grade you were in at these times.

> To me that was grade one. I can't remember grade two. I think I went from grade one to grade three.

Devastating Truth

When I complied the chronological list of your school years I spent time trying to figure out how old you were each year. While doing this I realized that you had never used age as a marker in the telling of your school story. I wondered if it was because you didn't remember or if it was too painful to face. I had said to you, "You were sixteen when you went to Drumheller. They put you in an elementary school with little kids. That must have been devastating" (conversation transcripts). Quietly, with a shaken voice, you said, "I know"

(conversation transcripts). I have few words that represent how you struggled to share this reality with me. However, I can remember the feeling of dread that filled my body as I saw your eyes fill with tears and as you said,

"I was.

I am.

It is really hard.

Who can you blame?"

(conversation transcripts).

Piecing The Puzzle Together

Grade two was very puzzling and troubling to you because you were unable to clearly recall it. Your voice changed while you tried to determine what grade you were in after year one. Your confusion was unsettling as you searched for a way to name these years. There was a sense of distress as you tried to find the lost year. As you searched your memory you began to recall that you had actually failed grade one.

> So to me that was grade one. I can't remember grade two. I think I went from grade one to three. That was a regular grade one class. I failed that. I actually failed that (conversation transcripts).

I sensed revisiting the fact that you had failed caused you great difficulty. It seemed that this failure caused you to dissociate yourself from this year.

> I remember where the school was, even today, but I can't picture what grade I was in ...We moved and I can tell you exactly where the school was in Calgary. But do you think I can remember what happened. Mom and dad say I was a good student there. But why can't I remember? That part is just blanked out. I don't even remember the teacher and that is the sad part (conversation transcripts).

Your dissociation with this experience of failure and retention is reflected in your forgetting what you had experienced at the time. It took repeated conversations before you were able to clearly place this missing year.

> Grade one was a regular class. I failed. So I went to grade one again in Derwin. I asked my mom. But I didn't finish grade one there. That is when we moved to Calgary. Then we moved to Calgary and again I took grade one and two.

Concerns about the possible negative effects of retention on students have been expressed since the 1930's (Dawson et. al, 1988). *However, the practice of retention continues to occur despite the research that shows the negative effects of retention do not outweigh the positive effects* (Berliner, 1986). *Some of the negative effects from repeating a grade noted are: students show characteristics of learned helplessness; students tend to attribute failure to themselves and deny their part in their own success; students learn less in their second year; and that students have negative attitude towards retention* (Dawson et. al., 1988, Ascher, 1988). Herb, your own experience seems to resemble what the literature states as the negative effects of retention.

Helplessness expressed itself in your feelings that you were not gaining educationally. However, you were required to continue to attend school for you saw no other options.

> I just lost, I just lost you know. In a way it is bad that a student can't tell a teacher it is time to move on. ... there was times that I told them that it was a losing battle. I wasn't getting no where. Like my mom and dad even today, they say that they should have pulled me out of Mario Rose school. I wasn't doing nothing. It wasn't me you know. They weren't giving me the education (conversation transcripts).

You saw yourself as having a role in the failure you experienced. You struggled blaming others but you were comfortable stating that you had to take ownership for your lack of success.

> If I had it to do again I would try my best in getting a better education than what I got. You know I could if I could go back I would try harder (conversation transcripts).

While you repeated grades throughout your schooling you never spoke about finding these experiences beneficial. Retention contributed to your lack of self confidence, a feeling of humiliation and repetition of the same work.

> It was scary. You know I wasn't going to get nothing out of it. You probably feel the same way as I did. When you just learn something you've been taught, you've been taught all your

> school years. You get to the point that you're just tired. That is the way I felt (conversation transcripts).

Retention for you, I believe, was a negative experience. This is reflected in your response when I asked how you felt about being in grade six when you were sixteen years old. You do not express anger towards the experience of retention directly. However, much of what is under your words is your negative feelings about being retained in different grades throughout your school years. Your school experience was, and is, reflective of the outcome of retention and its' effect on students.

Your Dilemma

In our first conversation you blamed your grade one teacher for the beginning of your lack of success in school. However, you felt anxious about blaming her. In a subsequent conversation when I had asked you to respond to what I had initially written about your school story, you shifted the blame from your teacher to the Board of Education.

> Maybe in a way it was her fault but in a way it could be the way the teachers were educated then. So instead of blaming the teacher, I blame the Board of Education (conversation transcripts).

In further discussion you provided additional insight as to why you thought your education was the way it was. You moved the blame away from the Board of Education to the way education was delivered at the time you attended school.

> Maybe she did try but you know the way the school system was and is today is different. Like all these conferences you hear more. There is more and more education for parents with disabled children. Back in the sixties just like watching the movie today what it was like being put in the institution. All you did was watch TV for 24 hours. Then gradually the years moved ahead. They got people involved in crafts and you know learning. I figure with school boards it took slow progress to say you know the system has to change. We can not neglect these people anymore. We can not criticize, now disabled people have a right (conversation transcripts).

As I listened to your words and read the transcripts I came to understand that you did not feel anger toward educators. You are a person who is even-tempered. Anger is a painful emotion for you and you avoid expressing your thoughts and desires this way.

> I hate fighting because it don't get you no where... how can I blame my grade one teacher when I actually know what was actually going on with education back then...
> I'm a person who tries to get along with everyone. You know even though what those teachers did to me, there is a part of me that hates them for what they did, but there is another part saying it is not their fault. They needed help (conversation transcripts).

Allport (1954) concludes that *"... being a victim oneself disposes one either to develop aggression toward or sympathy with other out-groups"* (p. 155). Although, teachers are not considered an out-group in society, your own personal experiences seem to have made you more sensitive to being critical of others. You find it difficult to blame the school system and your teachers. However, you see yourself as playing a part in your failure in school.

> I always think that I was guilty, I feel guilty because I know I should have paid attention. I look back and figure how could I change (conversation transcripts).

Your comments point to the notion that you see yourself as having a responsibility for your difficulties in school. You have taken the blame for this situation upon yourself. You see yourself as having played a major role in your school failure.

Abandonment And Betrayal

Herb, it became evident to me in listening to your school story that you felt a certain amount of abandonment and betrayal. You wanted your teachers to help you gain a sense of accomplishment. You had a desire to be considered worthy of your teachers' attention and time no matter what your ability at the time. Sarason (1982) echoes this sentiment by stating, *" ... the recognition, understanding, and acceptance of diversity are among the most important experiences any person can have"* (p. 271). This is not what you experienced. What you experienced was a sense of abandonment.

> That is when they knew I needed special attention. They didn't really have the time for me... I think if I had got a lot of support when I was in grade one, like if the teacher really took ambition, really cared... Where was she when I needed her? (conversation transcripts).

Although you felt abandoned and betrayed you had no choice but to remain in the school situations offered to you. The school districts could do as they pleased while your disability took the blame for your lack of success. Not only did you feel helpless in not being able to break out of this spiral but so did your parents.

> There were times that I told them [parents] that it was a losing battle. I wasn't getting no where. Like my mom and dad even today say that they should have pulled me out of the segregated school because I wasn't doing anything. I wasn't. They weren't giving me the education. Like what could I do. That was the school that they put me in. There was no other (conversation transcripts).

This continual rejection and lack of support was a constant threat to your self-esteem. Your struggle to resist this abandonment was not taken seriously. You were continually forced to endure the hurt of being shipped to yet one more place. It was not until your teen years, close to the end of your public school education, that your sense of abandonment was affirmed.

> The year Mr. S. threw down that math book I didn't have a clue. In a way I knew what it was but he said this is times and divide. I told him what is this. He said this was times and divide. I don't know how to do it. It really shocked him. He was so upset. I heard someone say that he actually went back to my past school and gave them his two cents (conversation transcripts).

In telling this story, I heard a sense of relief in your voice. Finally you met a teacher who showed concern and was upset because you had not been challenged to your full potential. Mr. S. saw you as the able person that you viewed yourself to be. As a student you longed for such a teacher who would be supportive and caring.

Mr. S.'s actions are reflective of what Noddings (1982) calls an *"ethic of caring"*. Your situation confronted Mr.S. with a moral situation.

> *"In this type of moral situation, welfare of others is at stake as a result of some predicament or circumstance... When a caring person is confronted with this type of situation, his or her desire for the welfare of those in the situation is either a desire to help or (if not in a position to help) a desire that someone help"* (Shogan, 1988, p.17).

Mr. S. acted upon his own will to address this situation that he saw as an injustice - the poor quality of education that you received.

Sent Away

> That is when they moved me again to this other school. Where they, where I knew I wasn't getting nowhere. I made excuses and I was sick. I think at that stage it just got to me. I wasn't getting no where. So I just lost interest.... I actually went to my parents. Mom and Dad even said I wasted a school year there (conversation transcripts).

This school placement caused you to begin to question the usefulness of the education you were receiving.

> Then after Rockyford we moved to Calgary. That is when I went to another school in Calgary. That is when they found out I needed more attention. That is when they moved me to a different school that was downtown Calgary. I think it was close to the hospital but I can't remember. It was around Stampede Park. I know that. I didn't care for that school. I actually missed a lot of days. I just didn't feel like going to school (conversation transcripts).

While talking about this you became more distressed. You had been in special education before so I wondered why this placement caused you to doubt the usefulness of the instruction being offered. In listening to you I realized that this was the first time that you had been sent to a school that was different from your sisters. When I pointed this out you said;

> That is true. You know in a way I thought why was I different? I knew school was hard for me and the special education classes were helping me but doing the same thing over and over .... My sister was going to Forest Lawn and I was going downtown. ... I had always felt comfortable because I knew my sisters were in the school. They were right in the school yard. Now I felt uncomfortable (conversation transcripts).

You went on to say that being moved away from your neighbourhood school caused you to begin to view yourself differently. What seemed like a simple act to the board of sending you to a different school presented you with the notion that you were different. Your sense of difference was felt in many ways. One of these was feeling disconnection from your peers and siblings.

> When I was with friends I knew I was in a different school and I wasn't with them (conversation transcripts).

Until this move you experienced the ordinary social and recreational life that all students enjoy in their community school. This disconnection continued to occur whenever you were placed in a school separate from your neighbourhood peers.

> I remember that they sat me down and told me that they were going to move me. At that time I was a safety patrol. ... What really hurt me was I had to step down from being in the

> safety patrol. Learning that I had to leave that school and leave the safety patrol, it was hard (conversation transcripts).

You had encountered many transitions within your school years. These moves encapsulated the complex and multi-dimensional nature of transition and change. Not all change is sought or welcomed. You were forced to endure many involuntary transitions. Some of the moves were due to your father's employment but many were due to the boards' decisions to move you to alternate programs. The themes in these transition were isolation, rejection and despair. Some of the moves really hurt. Being sent away meant leaving your sister, your neighbourhood and the most cherished thing of all, something you were good at, something that gave you value and worth, an identity in the school, - the "safety patrol". *"A sense of identity is not easily achieved. People with learning difficulties are faced with obstacles at every turn. Their stories witness their battle, often life-long, to overcome these obstacles and find a sense of self"* (Atkinson & Williams, 1990, p. 217). Being sent away, once more, made it harder for you to find and secure a sense of self.

"Good" Teachers

In your third year of schooling and then again in your last two years of schooling you encountered teachers you named as "best" teachers.

> That is where Mr. S., one of the best teachers... I would say out of all my teachers that really took time and the energy and really showed that they wanted me to get something out of life was Mrs. W and Mr. S. The others I really can't say. It

> really upsets me because you know now I'm grown up and you know I look back and you know I could have been this if teachers had taken the time. It is the way I see it today (conversation transcripts).

For you a good teacher was someone who was interested in taking the time to help you accomplish something.

> They looked at their students like even they are smart. Let's prepare them so that when they grow up they have something to go on.... Like she even helped me when I was in Cubs. Like she took time to help me, took the time to help with what I had to do for Cubs, make a flag (conversation transcripts).

Later in our conversation you made reference to another teacher who you believed to be good. He had organized the school patrol which you were a member.

> The teacher that give it to me [the award] was the one that if he had the time he would have probably quit his job and took time to teach me (conversation transcripts).

Your description of a good teacher reflects your desire to be in an authentic connection (Mikel & Gilligan, 1992) that gives you the sense of being heard, responded to empathetically and able to believe in your own experiences.

> Today, Mr. S. sure he is a teacher but he was more of a friend too, that is one thing that is really important for a teacher today is to be more than a teacher but also be a friend. So a student can have trust. It doesn't always have to look at you as a teacher. He can look at you as a friend. A person, that if you have problems you can go and talk it out. And that is what I found in Mr. S. And that is why we have a friendly relationship, even today (conversation transcripts).

It is not surprising to me that what is important to you is being in a relationship with your teacher. Relationships that create an atmosphere of trust and support between the teacher and student are essential to you in the classroom and in your everyday life. Teachers that formed relationships in and outside of school with their students were essential to your understanding of a good teacher. *Your way of knowing is rooted in connection with others* (Belenky et. al., 1986).

Diminished Expectations

> That is where we watched Sesame Street every morning. ... And then there was Mr. Peabody cards. I didn't get anything out of it. .... Every morning we had to watch Sesame Street. Like there were better things you know. I think the teachers were wrong. If they took time from Sesame Street and taught us math or spelling. It was frustrating because at that time I didn't know what my rights were (conversation transcripts).

What strikes me, as I heard you say this, is knowing that you were not a child but a teenager at the time. There seemed no focus to what you needed educationally. I sensed that the school district was at a loss in trying to figure out what to do with you. Sending you to the segregated school meant that they didn't need to worry about you anymore. There was no concern about whether this educational environment would meet your needs. The focus seemed to be that you would have to learn to fit into what the teachers already did at the school. Your needs would not be the focus. I think of the words of Elizabeth Pieper who states when reflecting on her own sons treatment in special education, *"... he was discriminated against for a handicap which he could not help. And that was almost too nice a way to think about it. It was a punishment. In a more humane culture, he might be given extra help. Now he was abused"* (p. 49).

> Why bother. You go to the same class and you are learning the same thing over and over ... I was given the same thing over and over, you know. You get a job where you do something over and over and over. Eventually you are going to get sick of it. They were giving me the same stuff over and over. I wanted to learn something new. You know they didn't change... You know watching Sesame Street everyday you just get tired. I wanted to keep myself busy doing math or something. To me it was rest time for the teachers. Just picture back what that was like. I'm glad they closed that school down (conversation transcripts).

I Could Have Been Someone

> It really upsets me because you know I'm grown up and you know I look back and you know I could have been this if teachers had taken the time. It is the way I see it today (conversation transcripts).

Productive, socially valued achievement is at the heart of our western culture. Sarason (1982) states,

> *"It is hard to overestimate the importance we place on achievement, and the psychological debilitating consequences the lack of achievement so frequently has in the lives of people. The sense of unworthiness people may have because of their lack of achievement reflects how well society inculcates in us its importance"* (p. 262).

Your desire to be more than who you are is common. I believe educators are, and were, sympathetic to your desire to achieve more. However, this sympathy would have faltered when support to you interfered with society's values of developing productive students in a socially valued way. It was easier to place you in special education than to provide you with the support you needed to be able to achieve in the regular class.

> You know there are other risks that I would like to try but you know with not having an education ... If I could turn things

> back I could have had an education. I would like to be a person that works in an office (conversation transcripts).

Herb, these conversation threads illustrate for me your on-going struggle with your perceived academic ability and how it has manifested itself in the career choices you see available to yourself. Your struggle is a linking of your past, present and future and how your lived story is a reflection of your view of your limited academic skills. Your identity is tied to what schools most value, the accomplishment of the curriculum. It is the stuff of our schools. You are driven by the anxiety of not performing. This anxiety manifests itself in your fear that you can not be successful in other jobs.

I Will Do It On My Own

> I knew I was losing out. That is when I figured this is where I have to do something for myself even if I don't have an education. Darn it, I'm going to make myself, I'm going to make something of myself with the education I do have. ... What I learned in my school years was that if they weren't going to teach me I was going to teach myself but I didn't know how. I was determined that is as going to get myself a job where you know I could be proud. I wasn't going to be a beggar on the street. I was going to make something out of myself, even if no one was going to help me, I was going to do it (conversation transcripts).

Herb, you had felt disadvantaged within the educational system as a child and much of your story has been your personal struggle with the obstacles schooling placed upon you. However, your personal struggle finds expression in your securing meaningful employment.

Conclusion

Throughout your telling there is insight and wisdom. You have insight that touches the soul and there are moments in your story that are neither dramatic nor touching. They are mundane and ordinary like the major parts of many of our lives, yet they are still representative and significant. I have struggled throughout the telling and writing of your story because of the emotionlessness with which you tell your story. I had wished for the dramatics of emotion. You occasionally showed the hurt and distress you experienced. I wonder if the expression of hurt, dejection and anguish has been something that has been discouraged in your life. Self-respect and dignity are crucial principles of survival. You do not want to be seen as a victim but as someone who maintains some semblance of contentment with life. As the researcher I honor this for this is who you are.

Working with you I have discovered that there is dignity in being listened to and taken seriously. You searched hard for an identity and you have found identity in telling your story. Through the telling you felt that your life and story has value. You have been very proud of your involvement. I know this because you have spoken about it to other people as something that not only pleased you but which you saw as a real accomplishment. Being a participant in a research project has brought you the reward of social recognition. This has been a valued social role (Wolfensberger, 1972). Valued social roles are rare experiences for

you. Through telling your story you have a sense of achievement. You have felt affirmed.

CHAPTER FIVE

Introduction

During the time I listened to Percy's and Herb's stories, I studied the existing research literature in search of connections between their stories and research in developmental disabilities. The research literature helped me to put my reflections and my research participants' stories into the context of the construction of disabilities. While preparing to pull out the common themes between Percy's and Herb's stories, I realized how in many ways, their stories parallel the stories of students I have taught in special education. Percy's and Herb's stories reawakened in me many of my own stories of teaching. Through reflection on their stories and the existing literature I have come to understand new meanings in my teaching and new ways to understand the possible experiences of students I have taught.

This chapter is structured to reflect my understanding of the literature, to reflect Percy's and Herb's common experiences, to reflect my images of my students' experiences, and to suggest new and different stories.

The Construction Of Deviance

Bogdan and Taylor (1987) state that historically research about individuals with developmental disabilities focused on how individuals have been abused, neglected and dehumanized in society. The dark side of individuals' lives and the characteristics of deviance (Goffman, 1963) have been the dominant themes in research.

> For a quarter of a century sociologists have concentrated on stigma and the labeling and rejection of people with negatively valued physical, mental and behavioral differences (deviant, different or atypical) (Bogdan & Taylor, 1987 p.34).

They argue that this focus on social deviance has led to the exclusion rather than the inclusion of people with developmental disabilities in society. Bogdan and Taylor (1987) state that the most extensive work in sociology on deviance, a text written by Becker (1963), warned that research on social deviance should not be to banish people but rather to understand patterns of inclusion as well exclusion.

Research focused on how the social and cultural phenomena places people labeled developmentally disabled "in a deviant social role, subjected to stigma and rejected by the community at large" (Taylor & Bogdan, 1989, p. 22). They conclude that in our society if you are viewed as different, and if the difference is viewed as negative, the individual will experience repercussions throughout their lives. Once seen as less valued, society treats the individual in a negative way.

Taylor and Bogdan (1989) note in their research four main insights: first, "mental retardation is a social and cultural construct"; second, "the label of mental retardation carries with it a stigma"; third, "labeling someone as mentally retarded creates a self-fulfilling prophecy"; and finally, "institutions and organizations designed to treat or care for people with mental retardation create or reinforce behavior that further distances people with mental retardation from the broader community" (p. 23-24).

I see these four insights as central themes in Percy's and Herb's stories. Their lives reflect the common themes of individuals labeled developmentally disabled. The experiences of the students I taught in special education are also reflected in these four insights. These four insights form the frame which I will use to reflect on the participants' school stories and on my reflections of my students' experiences.

Insight One: Disability Is A Social Construct

There is a prevailing assumption that disabilities are human pathologies inherent in the individual. However, there is an opposing view that disabilities are not human pathologies, but are rather social and cultural constructs (Skrtic, 1991, Hahn 1989, Bogdan & Taylor 1989). Disability, in this view, is culturally relative rather than inherent in the individual. Wolfensberger & Thomas (1983) states that although different cultures define some differences as disabilities, what is, perceived as different falls into one or more of three broad categories.

> (a) physical differences and bodily impairments that exist from birth, or that occur later because of disease, old age, or other reasons; (b) overt and covert behaviors (the latter including religious, political, and other beliefs); and (c) attributive identities of people, such as dissent, nationality, the ethnic group from which a person derives, the language he/she speaks, or even a person's caste regardless of appearance, behavior, language, etc. (p. 23).

Within western culture, individuals labeled with developmental disabilities are seen as different. Their differences are labeled as disabilities and, therefore, they are subject to being treated differently. If a person is defined as deviant by their society, then they will experience devaluation and rejection. When services and supports are designed with the assumption that disabilities are inherent in the individual, limitations are placed on the labeled person. When an individual does not succeed, the fault is placed on the labeled individual rather than on the structures framed around the person.

Percy And Herb: The Construction Of Disability

For Percy, the construction of disability began at an early age.

> It started at an early age when I went to New Hope. It continued when I was in the special education class. Those that were in there we were always excluded from the larger group. They didn't want us to learn because we were retarded (conversation transcripts).

The construction of disability began when Percy was placed in a segregated school for children labeled mentally retarded. The feeling of being disabled remained with her throughout her schooling, even when she was transferred to a public school and placed in a special education class.

For Herb, the construction of disability was less clear. However, when he talks about how he was treated in school it is apparent that he was viewed as different. Therefore, it was acceptable to treat him differently from his non-disabled peers.

> You're closed down in the world. You're closed out. You are in your own group. What I think is they should be mixed in with everyone else. Even though they may be slow or you know that they might be smart in something. You got to remember we are all handicapped (conversation transcripts).

For Herb being educated in a different environment meant being cut off from the world. One way the construction of disability occurred for Herb, was by his placement in a segregated school. He struggles with this because he sees himself as more alike than different. He wonders why others see his disability as the defining factor of who he is and where he should be educated.

I once heard the phrase "six hour mental retardation" used to refer to the experience children with developmental disabilities have in school. While in school the individual's differences are perceived as a disability, while outside of school the individual's differences are less apparent. While in the public school system the label of "developmentally disability" was debilitating for Percy and Herb. The construction of disability began when they entered school.

A Teacher's Account: The Construction Of Disability

Through the process of this research, I have seen many examples of the construction of disability in my teaching. The student I referred to in the beginning chapter has helped me understand this. When Kevin was in special education he was believed to be very dependent on others to complete tasks. For example, on field trips when Kevin wanted to order a soft drink from a restaurant kiosk, he required almost complete supervision to execute the

request. An adult had to shadow him throughout the task and prompt him to make the verbal request to the clerk. As his teacher I continued, with great effort, to try and decrease his level of dependence in completing simple tasks. While I was his teacher, we were unsuccessful in accomplishing this goal. I believed Kevin would always need support. After all he was labeled "severely dependently handicapped".

When Kevin began to attend his neighbourhood school with his non-disabled peers, I had time to observe him. On one occasion about six months after his inclusion in the high school, I arrived just before the morning nutrition break. During the ten minute break, students rushed to the school store to purchase snacks. When the break bell sounded, Kevin left the class independently and headed towards the school store. He, along with at least 80 other students, crowded into the area. I watched Kevin from afar and was astonished at what I observed. Kevin without support successfully ordered and paid for a soft drink. If I had not seen it myself, I would not have believed this was possible. Why could he now do something that we had tried to teach him unsuccessfully to do for four years?

I wondered what the two environments have to do with the way Kevin responded. While in the segregated class, we believed he would always require support. Our efforts were half-hearted because we didn't really think he could do such things independently. In the high school he was treated more like the other students and was required to accomplish many more things by himself. However, there was more at play concerning his learning in these two environments. I believe we had seen him as more disabled in the special education class; therefore, he responded as more disabled. Our attitudes and beliefs about people labeled "severely dependently handicapped" contributed to our expectations.

Insight Two: Stigma Of Labels

> ... labels are arbitrary constructs which purport to describe "reality" but actually shape it according to a cultural preconception (Miller, 1990, p. 67).

The term “developmentally disabled” carries with it perceptions and attitudes about the individuals placed in this category. The attitudes and perceptions are reflective of our culture not of what is inherent in the individual, nor are they objective characteristics of the labeled individual (Sarason & Doris, 1979). Bogdan and Taylor (1987) argue that, "(m)any atypical people are made total outcasts by the social processes conceptualized and documented by labeling theorists" (p. 35). The view that people with developmental disabilities have "internal traits of so-called personal deficits or deficiencies" (Hahn, 1989, p.227) results from the paradigm that labeled individuals are inferior. The label of developmental disability carries with it a stigma. Edgerton (1967) writes,

> The label of mental retardation not only serves as a humiliating, frustrating, and discrediting stigma in the conduct of one's life in the community, but it also serves to lower one's self-esteem to such a nadir of worthlessness that the life of a person is scarcely worth living (p. 145).

These views are based on the attitudes of people who attach these labels to others, rather than to objective conditions (Bogdan & Taylor, 1982). Proponents of disability as a sociopolitical definition believe that developmental

disabilities are social and cultural constructs and not something inherent in the individual. The label becomes the all-consuming characteristic that defines the individual.

Labeling is very much part of the education system.

> Schools serve as the great labelers in our society, assigning names to children (mentally retarded, emotionally disturbed, etc.) that even if they turn out to be totally inappropriate may have severe negative implications on an individual's failure (Apter, 1977, p. 107).

As a child begins to encounter difficulty in school she is usually referred to experts who are requested to identify the child's difficulty. Often the response is to give the child's difficulty a label. This label increases the child's chances of being referred to a special education class. The focus is generally on providing a label and identifying the child's deficits rather than providing alternative instructional strategies within the regular class.

> The case records of students classified as disabled bespeak deficits: "moderately retarded student unable to communicate in complex sentences", "not capable of fully independent living without support"; "has difficulty making friends"; "age 15, reading on grade 2 level"; "poor impulse control, student requires close supervision and management." Such records are littered with deficit labels and statements that sound more like conclusions than prognosis (Biklen, 1992, p. 10).

Percy And Herb: Stigma Of Labels

Both Percy and Herb referred to being tested. Herb describes what he thought the purposes of these tests were and what the tests measured.

> I remember going to a hospital. I think it was a hospital, a hospital or a university. No, it was a university. ... I was tested like they showed you, you did blocks, then you did puzzles. They show you pictures of scattered art and they ask you what you thought that picture was. ... To me it didn't bother me. You know in a way I guess it was just for them to find out what my high IQ was and my low IQ. I don't think they were meaning to hurt me or test me. They were just trying to figure out where I belonged. But you know, they didn't really get to spelling and math. You know, they didn't test my skills with that (conversation transcripts).

I am struck by Herb's words "... they were just trying to figure out where I belonged" (conversation transcripts). In these few words he captures, with clarity, the intent of the testing. I wonder if being "sent away" (Kidder, 1989) was at the heart of this exercise. Was the testing to provide the final ammunition to rationalize why Herb no longer belonged with his 'typical' peers? Herb said, "I don't think they were meaning to hurt me ..." with such a sense of trust. I do not believe the intention was to hurt him, but I wonder as a teacher/researcher how many children have been hurt by the use of IQ tests, as means to determine if a child should or should not be educated with his peers.

Percy's experience is one of wonder. She questions why one would be required to participate in such an exercise.

> They wanted to find out what my disability was. I can remember being brought into rooms and I had to put blocks together. The second part of the test, this is funny, I didn't do what I was supposed to do. The first day I did whatever I was supposed to. For some reason the person that was testing me, I could sense that he had a degrading attitude. I felt like he was just doing his job. I didn't want to go (for the testing the second day) because I felt that they were criticizing me. I remember telling him "why don't you just ask me." I was stuttering, but that is what I said. I remember feeling angry, a lot of anger, but I did what I was supposed to, but in the end I pushed all the blocks on the floor. He didn't really do anything. He took my mother into the another room and they talked. They didn't talk to me. I was never included. They never told me the results. They never asked me questions. Like things like 'what do you like' and 'how do you feel' or 'what do you see'. Everything was so structured. You have to go within the structure and you have no room to move. You're like an obstacle (transcript conversation).

The testing used to determine Percy's label caused her, once again, to feel unwelcomed and worthless. An IQ score was seen to be more valuable than how she felt, saw, and thought about the world around her. The labeling was one more rejection. Percy was expected to perform the tasks, not to question their

purpose. I wonder what was written about her response of knocking the blocks off the table. Did this assist the educators to rationalize that she really was not worthy of being with typical children, that her behavior was unpredictable and warranted segregation to protect herself and others?

The testing of Percy and Herb did not seem to provide either of them with alternate instructional strategies to help them learn. In spite of the testing, Percy and Herb both seemed to continue to receive more of the same.

Neither Percy nor Herb use disability words to describe themselves. These labels are insignificant to them when they describe their lives. It is not that they do not realize that they have limitations, but rather the words do not adequately describe who they are. For both of them, labels do not help others to know them. For example on one occasion Percy, after using the word "retard" said, "I hate that word, but I have to use the word in this instance. I'm using it because that was the past and that is the way it was" (conversation transcripts). Pat Worth, Past President of People First Canada, an advocacy group for and by people with developmental disabilities, wrote his views of labels.

> "Nobody has the right to label someone 'retarded' he says; "The label is a kind of punishment that stops people from getting jobs and prohibits them from living in the community. It is demoralizing to see someone as a label instead [as] someone," he writes. "I am a somebody. My name is Pat Worth. I am not retarded. I don't think anyone is. I think labels are unnecessary" (Biklen, 1992, p. 11).

For Percy and Herb their experience has been that the label 'disability' became the all-defining characteristic of who they were. It determined where

they went to school, who they associated with, and where they played. The social construct of disability haunts their past, present and future.

A Teacher's Account: Stigma Of Labels

In reflecting on my experience as a special education teacher and in listening to Herb's and Percy's stories, I gained new insight, a spirit of "revision" (Connelly & Clandinin, 1988) as to what my awakening had revealed to me. As a special education teacher, I practiced under the assumption that disabilities are inherent in the individual. My personal awakening brought forth an understanding that, as a teacher, I operated with the stereotype that people with developmental disabilities were less worthy, less equal.

As a teacher my relationships with students were framed by rejection rather than acceptance. This statement sounds harsh; however, I believe this is reflective of the image I had of the students. Their labels were central in our relationship. They were worthy of instruction but only in a segregated environment for they were disabled and were different from the other children in the school. They needed to be separate from their peers for they may have disturbed or interfered with the 'typical' students' learning. Mrs. D.'s request for her son to go to his community school forced the beginning of my "awakening" and helped me understand how viewing children with developmental disabilities as less worthy was destructive. Viewing the child's label as the most salient characteristic could and would limit their potential. The label was destructive in helping me as a teacher to best educate and develop relationships with my students.

Insight Three: Self-Fulfilling Prophecy

The label "developmental disability" carries with it a stigma. Labeling a person as developmentally disabled also creates a self-fulfilling prophecy (Taylor & Bogdan, 1989). Role expectations are placed upon the people within these circumstances. Wolfensberger (1972) found that people generally play out the role in which they have been cast.

> This permits those who define social roles to make self-fulfilling prophecies by predicting that someone cast into a certain role will emit behavior consistent with that role. Unfortunately role-appropriate behavior will then often be interpreted to be a person's 'natural' mode of acting, rather than a mode elicited by environmental events and circumstances (p. 16).

The roles in which we are cast have considerable effect on our behavior. Wolfensberger (1972) refers to the work of Rosenthal and Jacobson (1968) to illustrate how powerful role perception is on the development of children. He goes on to say:

> ... it appears quite consistent with the well-documented fact that retarded children who are placed into special classes underachieve grossly when compared to their retarded peers, who are carried along in regular classes even without any special attention (p. 31).

The role perceptions and stereotypes not only affect the behaviors of those labeled but also those who surround the labeled individual.

> Of great importance ... are labels, concepts, stereotypes, role perceptions, and role expectations that are applied to a person and that often determine the circularity between his own self-concept, the way others react to him, and the way he is likely to respond (Wolfensberger, 1972, p. 31).

Percy And Herb: Self-Fulfilling Prophecy

> Yeah and we were learning these cue cards every time. It seemed like it was never ending. It was like we were learning the same words over and over. If we did a good deed, you would get a star and after so many stars you get a choice to pick a toy. Yeah a toy. She used to treat us like little kids (Herb's conversation transcripts).

In each of our conversations Herb spoke of his struggle with being required to do the same work over and over, as well as of his questioning of the work he was required to do. He wanted the teachers to provide him with more challenging work but due to the perceived view of his ability, he was relegated to do simple repetitive work.

For Percy there was a feeling that the work she was required to do was of little worth. She was not given the opportunity to learn the same subjects or content that her non-disabled peers were taught.

> In terms of I never learned anything. When I was in New Hope I remember learning how to wash the dishes. ... The men had shop and we had cooking and learning how to wash the dishes and sweep the floor. ... They called it social studies, it was basically, they didn't teach what the other students learned. It was always Mickey Mouse stuff (conversation transcripts).

The placement of Percy and Herb in segregated education contributed to the devaluation of their perceived worth. They were educated in environments where the prevailing attitude appeared to be that individuals with a developmental disability were not expected to learn. This attitude is the underlying principle of a self-fulfilling prophecy. This self-fulfilling prophecy operated to produce their sense of inadequacy to learn.

A Teacher's Account: Self-Fulfilling Prophecy

As I listened to Herb's account of doing the same work over and over and to Percy's feeling of doing useless work, my mind was filled with teaching memories. As a special education teacher I believed that repetition and direct instruction (not always in context), was the most effective way to instruct students who had been labeled autistic (Jordan, 1972, Snell, 1978, Koegel, Rincover & Egel, 1982). The instructional programs in the class were designed with this in mind. Teaching was based on the students' perceived deficits and we taught to these specific skill deficits.

Kevin, one of my students, had limited communication skills. A program was designed to increase his vocabulary. Every day, for 15 minutes, he was

shown pictures which he was required to label. My memory of these lessons were of their tedious nature. Kevin never refused to do the task and his vocabulary did not develop extensively. However, when Kevin was integrated into his neighbourhood high school, it was reported by his mother that he was more enthusiastic about his learning and that his desire to communicate with others had increased drastically. Once Kevin was included in classes with his non-disabled peers the goal of increasing his vocabulary was still relevant. However, rather than isolated lessons with flash cards, the regular class environment provided a rich array of language as a model to stimulate his vocabulary.

The instruction in the special education class was framed on the belief that Kevin would learn little and, therefore, we needed to target the most important skills he needed and to drill them until he learned them. The approach actually limited his learning and motivation rather than increased his skills. The approach was never changed nor questioned because of the belief that Kevin had a limited capacity to learn. Therefore, we targeted what we deemed as the most important skills. When he moved to his community school, Kevin exposed all the myths about his capability to learn. In his inclusive school environment he quickly learned many of the skills he was drilled on for the four years in my class.

Insight Four: Distancing People

Research in special education supports the perspective that individuals labeled developmentally disabled are different than their non-disabled peers (Shanker, 1994, Fuchs & Fuchs, 1994). From this assumption, there is a rationale that disabled students should be segregated from their non-disabled

peers. The exclusion of children from the regular stream usually means placement in a special education class.

Placement in a separate class symbolizes for others that children in these environments are deviant and devalued because it is necessary to educate them in a different environment. According to Wolfensberger & Thomas (1983) special education classes may contribute to further devaluation of a student already at risk of devaluation and rejection because of their disability. The practice of grouping students with special needs increases the potential of their devaluation.

Percy And Herb: Distancing People

Percy speaks of how being taught in a separate environment contributed to others seeing her as being devalued and rejected.

P: I ran to the other school there. I didn't have the guts to ask can I play with you kids. I just stood there and watched them.

H: Do you have any sense of what the children in the other school were like when you were standing there?

P: They were very cruel. They said to me go back you retard. Go back to your school. They were very cruel.

H: I wonder what made them behave that way?

P: I assume now that I am an adult that it was taught to them that way. They see us as being segregated and they probably saw the way teachers treated us. So

> they figured we didn't know nothing, so they are nothing (conversation transcripts).

Percy's insight into how rejection is constructed is profound. For Percy, the heart of the matter is that how one is treated gives others a clear message. Keeping students with developmental disabilities apart gave the non-disabled students permission to reject the students in special education. Rejection is an experience we all encounter in school, but rarely has it been because of the way educators structured the learning environment. For Percy, rejection was in the hands of the adults. The belief that children with disabilities are best kept apart set the stage for her rejection to occur.

For Herb distancing came in the form of direct rejection by his peers. The fact that he traveled away from town for schooling added to the stigma. The exclusion of Herb from his community school contributed to his peers' belief that Herb was different, therefore it was okay to reject. This rejection was difficult for Herb, for I sense that being in relationships with others is a very important way of knowing for him. To be rejected by others was disturbing and uncomfortable for him.

> Like after school I used to drive into town. I took the bus home. That was really hard on me because the kids used to pick on me ... The students were not the best. They didn't really care for the most of us. ... that's where I just know, I just thinking about it, I wasted a whole year (conversation transcripts).

A Teacher's Account: Distancing People

In my reflections I became aware of how rejection is constructed through seeing one of my lived stories from a different perspective. I had taught for two years in a self-contained special education class for students labeled "autistic". Most of my students were able to converse with others and were working on academic skills from the grade one to grade six level. These students played on the playground and attended whole school functions with the rest of the school population. However, interactions between my students and the rest of the students were minimal.

In my third year at the school, two students, both considered "severely developmental disabled" began to attend the school. Their parents had requested they be included in a regular class rather than in a special education class. One was placed in the grade one class, while the other was placed in the grade three class. Both used wheelchairs to get around and neither could communicate using words. In the classroom their work was very different from their peers. The teachers focused on ways to help the students feel part of the class and to find personal connections with the instructions.

What struck me about their inclusion in the school was the way the general student body responded to them. They had only been in the school for six weeks and already most of the students knew them by name and approached them in a friendly manner in the hallway. On the playground they were surrounded by their peers who would eagerly push them around. It was wonderful to see. However, on reflection, it was clear this was not the experience my students had. They had been at the school for two years and no one seemed to know their names and rarely did anyone talk to them in the

hallways. There was a discrepancy between experiences of the integrated and segregated students in the school.

I now see that the general student body understood the students' who were being educated in the self-contained special education classrooms in different ways than the two students placed in the grade one and three class. Why did this happen? My students and these two students were all labeled developmentally disabled. However, the two students in the regular classrooms seemed to be more valued. The school had constructed socially valued roles and life conditions (Wolfensberger, 1972) for these two students. Being placed in the regular classrooms decreased the stigma of their negatively valued label. These two students were in grade one and grade three, not in the "autistic" class taught by the "autistic" teacher.

Wolfensberger & Thomas (1983) state that you need to understand the concepts of deviancy and devaluation to understand why being placed in the regular stream would be seen as a more valued social role and condition .

> A person can be considered "deviant" or devalued when a significant characteristic (a "difference") of his/hers is negatively valued by the segment of society that constitutes the majority or that defines social norms. While numerous differences do exist among individuals, it must be clearly kept in mind that difference by itself does not become a deviancy unless/until it becomes sufficiently negatively valued-charged in the mind of observers. Thus, deviancy can be said to be in the eyes of the beholder, and thus is also culturally relative (p. 23).

My teacher education was structured around the belief that the best way of educating children with developmental disabilities was in a segregated environment. I could not see students with developmental disability as being accepted as equal to their non-disabled peers. When I experienced this situation it did not bother me that the students labeled developmentally disabled were separated from the other students in the school. As an educator in special education I failed to question the place of segregation as an historical and social construct. I accepted the special education structure as appropriate.

The focus on exclusion has allowed for a one-sided focus with an abundance of literature that supports rejection rather than acceptance of people with developmental disabilities (Bogdan & Taylor, 1989). The social science perspective of deviance has become so widely accepted that there is minimal literature focused on the construction of acceptance, such as, the acceptance reflected in the stories of the two integrated students. At the time when I was faced with the two scenarios, integration and segregation, I was not distressed that my students were viewed as less valued. I did not even see it. At the time, I had a strong affiliation to the perspective that separate was better and not harmful. To maintain this point of view it was necessary to ignore what was occurring for the two children in the regular classes and to just believe that it was a fluke. It was easier to believe that this was an unusual situation and that there were still many benefits to segregation that would warrant my continued commitment to it.

It has taken much reflection and many experiences of seeing the benefits of inclusion for me to see that, "(s)schools devalue individual differences by excluding children with special needs from regular programs "(Blatt, Biklen & Bogdan, 1977, p. 109). As a teacher I have had to face this fact and to consider what it meant to me. I have had to decide if I wanted to contribute to the type of

experiences Percy and Herb encountered, or to help create opportunities for children with developmental disabilities that reflected the two children's experiences in the regular classroom. Over time it has become apparent that it is the latter I am interested in pursuing.

And Today ..... Stigma In The 90's

Many may argue that Herb's and Percy's school experiences are just a product of the time. Some may say that attitudes have changed significantly. However, I am not convinced that things are much different. The views that shaped the education program when Herb and Percy were in school are still prevalent in today's society. The following statement from the Alberta Teachers' Association report called "Trying To Teach" (1993), demonstrates how some teachers view children with developmental disabilities as a burden to society as a whole.

> An example is a dependent handicapped autistic 11 year-old boy who was integrated in my Junior Adaptation classroom. He was functioning at about 20-months-old level, with an approximate IQ of 25-30. Although appropriate programs focusing on his level of functioning were available and recommended, his parents adamantly decided it would be better for him to be integrated. The boy had also been integrated in our school for the two previous years. The cost of educating him, taking into account aide time, teacher time and consultant's time, was between $25,000 to $30,000 per year. In short, it cost between $75,000 to $90, 000 to

> educate him during the three years that he was at our school. Had he been in an ability appropriate program he would not have required a full-time aide and would cost far less money. Monetary cost was not the only "cost" of this integration. It reduced the overall preparation time that I had for the other students' program because I was responsible for setting up and monitoring two distinctly different programs. The students additionally "lost out" in learning through the number of disturbances created by this student. He would frequently cry out, make whimpering sounds, bolt across the room, lie upon the floor and giggle, and attempt to masturbate. How does this promote excellence in education (p. 5)?

While this view reflects a minority of those working with students with disabilities, the influence of such statements can still be destructive. This story is of the rejection of yet another student. Statements such as "a dependent handicapped autistic 11 year-old boy who was integrated in my Junior Adaptation classroom. He was functioning at about 20-months-old level, with an approximate IQ of 25-30" is simply name calling. There is no child in this telling. This story is about defeat and unwillingness to see a child outside of his labels. These words do not describe who this boy is and what he is able to learn. This paints a picture of a very devalued child. The blame of the placement of this child, which the teacher deems inappropriate, is put upon the parents. Neither parents nor child are given voice. The teacher's voice is more valued than those most affected.

When I read this piece I was struck by the teacher's comments that this child was integrated into her adaptation class. I struggle because this teacher is teaching in a segregated classroom. The teacher discriminates among children with disabilities. The system is so compartmentalized that someone could even be excluded from special education classes. Is this what happened to Percy and Herb as they spent their time being moved from place to place? They too were excluded from the regular class but also were sent away from segregated classes.

Using the argument that the education of this child is a drain on the financial resources of a school board directly contradicts the notion of equal access to education for all children. If we seek to deny one child an education on the grounds of inadequate financial resources, we must deny them all.

This attitude toward children with disabilities has also been expressed in more public forms such as in local newspapers like "The Edmonton Journal" . These articles speak of children with disabilities as less than worthy.

> Trying every method to teach every possible individual would be horrendously expensive - and the only way it could be done would be by robbing school programs intended for "ordinary" children and special-needs children who have demonstrated capacity to learn (Elliot, 1987, p. A13).

Further articles argue against the worth of spending valuable dollars on the education of disabled students.

> In fact, school districts - particularly districts such as Edmonton Public which attracts a disproportionate share of

> children with special needs - have to supplement the grants. And that means they have to rob other programs. There is no doubt that the choice is extremely tough. But when money is limited, difficult choices have to be made. Which will be it? Spending as much money as it takes to accommodate children whose handicaps are so extreme that they are barely able to react- or using the money to ensure a higher standard of education for children who can benefit? (Elliott, 1987, p. C1).

This journalist argues that labeled children are not worthy of the finite dollars available for public education. She argues that we must face the fact that some children are not worthy of our time and money and we should stop wasting our energy on them. When mainstream media publishes such statements for public consumption, how can children with labels be expected to survive in an environment that promotes and allows such horrific things to be said about children? There has been little or no public outcry against these statements. For these children in society are:

> ... children who do not attain intellectual achievement according to the established schedule and are considered failures, no matter what their other qualities and sensitivities (Miller, 1990, p. 70).

These writings remind me of the "... significant role of language as a tool of social control..." (Darder, 1991, p. 140). They present a picture of students who are devalued who are not worthy of the scarce dollars that should be preserved

for the "status quo". Percy's and Herb's school stories reflect a world of rejection and exclusion. Their education was founded on the assumption that students with developmental disabilities are passive recipients with limited capacity for academic achievement and personal relationships. As I look around me in the 90's and see the continued rejection of people with developmental disabilities, I am saddened for I wonder if Herb's and Percy's wishes will come true.

H.R: Do you think that was the best way to help you as a learner, to have you in special education?

H: No

H.R: What do you think should have happened?

H: Ah in a way, yes, yes, you also have to be involved with the other students. Even if you don't know how to do it. It gives you that ambition that I am in a regular class. It's like with these handicapped schools. Why are they schools on their own? I think they (children) would get more, I think people would learn of their handicap if they were put in a normal school... What I want to try to do is get people that are in segregated schools get them integrated into regular schools. ... What I want is, I don't want anyone to go through what I had to go through (Herb's conversation transcripts).

What Now?

The extensive attention given to the darker side has left us with little research on the acceptance of people with developmental disabilities in caring and supportive relationships. To move away from this negative paradigm of the worth of children with developmental disabilities, Bogdan and Taylor (1989) argue that research in deviance must explore the social construction of humanness. Research must focus on how accepting relationships form between people with a disability and those without a disability. In their own work they have discovered that;

> In such relationships the deviant attribute, the disability, does not bring stigma or discredit. The humanness of the person with a disability is maintained. The difference is not denied but neither does it bring disgrace (p.137).

Through my experiences, I have begun to understand what Bogdan and Taylor meant about seeing the humanness of the children I taught. The labels attached to the children I have taught have begun to make less of a difference to me. As a teacher I want to have the opportunity to construct new stories around new plot lines and to imagine different stories, stories of hope for full inclusion. I want my teaching stories to speak of acceptance and the brighter side of the lives of individuals with developmental disabilities.

Looking At The Brighter Side: A Need To Return

In my role as a consultant, I tried to seek out opportunities to better understand inclusion and how to accommodate children with developmental disabilities in the regular classroom. I organized and presented many inservices on inclusion. I based my presentations on my readings, my experiences with Kevin and my observations of other teachers' practices. After three years I began to feel uncomfortable about the talk. I needed to understand inclusion in an applied way. To do this, I needed to be in the classroom, in a classroom with a diverse group of children. I knew that the only way I would find this was to return to the classroom as a regular education teacher, not as a special education teacher.

I needed to be back in the classroom. I needed to understand the struggles teachers experienced when they were asked to include a child with a developmental disability in their classroom. With this in mind I applied for a combined grade 1/2 class at a school in my district.

Brian Arrives

In my second year at this school, Brian, a new student arrived three weeks into the term. Brian had just been apprehended from his family because his mother disciplined him by burning his back with cigarettes. In his previous school he had been in a segregated classroom for children labeled educably mentally handicapped. This was all the information I had when he arrived.

On his first day, he was very withdrawn, not willing to participate in any activity especially if he needed to be with other children. I tried to give him as much support as possible. I made myself physically available to him (i.e., holding

his hand, taking him to the next area during a transition). Brian appeared to feel more confident as the day went on. The children were wonderful. They seemed to sense that we needed to be kind and gentle with him. They constantly asked him to join them even though he refused every invitation.

Being Tested

As the week went on I remember being exhausted and close to tears at the end of many days. There were 29 children in the combined 1/2 class. The addition of Brian had really tipped the scale. He needed constant support to do everything. He refused to participate, he asked at least 25 times during the day to go to the washroom, he hit other children for no apparent reason, he destroyed property and he cried easily. Although I was feeling frustrated by Brian's actions I spoke only positively about him in the staff room. I felt that he belonged and I needed to support him in becoming a member of the classroom and the school. One way to do this was to present the positive parts of Brian's ability in as many places as I could.

But Why Do You Give Him So Much Attention?

One of the children in the classroom raised a concern that some children were getting extra support. She was referring to Brian. We talked about how different people needed different things to be successful. After I shared my feelings she said she understood. She then told me a way that she felt she had gotten extra help from me to be successful. I felt relieved that she could express examples of how she received support and of her willingness to see another

perspective. It was touching and reassuring to see that she could understand the need to structure our class from an ethic of care (Nodding, 1984).

As The Weeks Turn ....

Brian continued to have great difficulty in the classroom. On some days he would spend the whole day refusing to try anything, rocking and banging his desk, moaning and making noises, hitting children around him, breaking things and the list goes on. But on other days we would have small break throughs. He would be more willing to be part of the class.

I soon discovered that whenever the class routine changed, Brian reverted to negative behavior to avoid the unknown. On a scheduled trip to the local seniors' apartment building to sing, Brian indicated he was not going to join us by refusing to do any of the presented activities and by kicking and hitting his peers. Brian ended up staying behind with the classroom teacher assistant. I asked her to make the morning pleasant. He did not get to go; we didn't need to further punish him while he remained at school.

Progress

As the term progressed, Brian made progress. He was only refusing to do about 50% of school activities in comparison to the 100% refusal when he first arrived.

On another day Brian had lasted until 11:15 one morning before he needed to be asked to leave an area because he was refusing to follow class rules. He was slowly gaining control of himself, preferring to engage in positive interactions to gain attention.

Finding Ways To Include Brian

In math, I allowed Brian to chose the math tub he wanted to work with rather than assigning him to a tub. This opportunity for choice seemed to give him a sense of control over the situation. During group discussion, Brian was permitted to color while he listened. Having his hands engaged seemed to help him focus. Before every transition I would cue him five minutes before the change happened so he could be prepared for it. These were just a few of the adaptations made in the class to support Brian's inclusion.

Brian Reaches Out

In a class discussion the children were grouped together on the carpet. Brian was sitting beside a peer whose shoe laces were untied. He, along with another child, spent fifteen minutes trying to tie the boy's laces. Throughout the discussion, Brian added his personal ideas while he was trying to help his peer tie his shoe lace.

Peers Reach Out

During a game of Duck Duck Goose, I was concerned that Brian would not get chosen by his peers. He was still struggling with making friends. But I was proven wrong. One student picked Brian early in the game. I was proud and moved that this student reached out to Brian in such an important way in front of her peers. She reminded me that if I set the tone for acceptance, the children will follow my lead.

So What Do You Think About Brian Being Here?

In a quiet conversation with a child we were talking about having trouble remembering things. I had shared I had trouble remembering things too. I reminded her of an example when she had asked me for something and I was thinking about a hundred things and forgot what she wanted. She needed to follow me around the room and to pester me to remember what I said I would get for her. She then said to me, "It is like you're going all around the room must make you tired. Like when Brian doesn't do something." I took this opportunity to ask her what she thought about Brian. She said something to the effect that it was good because we were learning, that it was good this way, that we were learning to get along. There was this sense of caring for all of us as members of the community in her words.

A Colleague Questions

At the end of one day a colleague of mine dropped by my class. When she arrived I was cleaning up a mess that Brian had made in one of his disruptive moments. She asked me why I didn't have him do it. I said that I had just discovered some of it and I did not want to carry the problem over into the next day. I felt it necessary to help him have a fresh start to each day and not to bemoan the previous day's infractions. She asked me why I didn't send him to the office when he had a difficult moment. She felt that I was going to get parents upset because I allowed him to stay in the classroom. I struggled with these comments because, for me as a teacher, I had begun to live the story that

all children had a right to be in the regular class and I was responsible to help him find a way to be part of it.

I shared with my colleague that Brian had been in our class for 6 weeks and in this short period of time he had made great progress. He had been in a segregated classroom before he had came to our class. I learned that Brian exhibited all the same behaviors in the segregated classroom as he demonstrated in our class at the beginning of the term. The progress he made in our class, I believed, was possible because we were trying to create an environment in which he felt welcomed and in which he felt a sense of belonging. Along with this he was with his age peers who demonstrated that they wanted him to be part of their lives.

My colleague struggled with what I said. She often came after school to see how I was faring and if I had changed my view. I wonder if she thought I would eventually give in and suggest he leave my class for another segregated class or was she worried because he might be in her class next year?

But What About Help?

As time went on I had to admit to myself that I was feeling frustrated. I felt Brian should be in the class. However, the resources necessary to support him and myself were not in the classroom. I constantly struggled with not blaming the victim, Brian, for the lack of resources. It was not his fault that there was little additional adult support to assist me to help him become more successful. I knew his behavior would not change over night. It was going to be a long process but one worth enduring for, to me, the little changes already felt monumental for Brian.

A Telling Story

I often called Brian's foster mother to share with her how he was doing. I focused on positive examples of his behavior. One particular day I called with enthusiastic news about something he had done. She responded by saying something to the effect of, "You must be a leveled headed teacher to tolerate the type of things Brian does in your class. You always call to tell me the positive things about what Brian is doing rather than complaining about him." I wondered about this comment. Had her experience with other foster children been that the school called to express all the negative things the children had done? Brian's foster mother knew how difficult he was. She did not need me to call each day to add to her struggles with helping him to be more positive at home. It was the positive things she needed to hear. As his teacher I felt she needed to know how his behavior was improving, not to have me dwell on the negative.

A Short Stay

Brian was only with us for three months. He was moved to another foster home in another area in the city. I tried to make contact with his new teacher but was unsuccessful. I still wonder about Brian and the effect his peers and I had on his life in the three months we knew him. The children over the next few weeks commented that they missed Brian. I wonder if they, like me, had seen the progress he had made. I still wonder, if he had stayed with us, how much more progress he would have made.

Why Did I Persevere With Brian?

Why was I persistent in my desire to help Brian be part of our class in spite of the energy it took? Through my awakening, I had come to understand the parents of the children I taught wanted and needed me to care for their child, to see their child as a child first, a person that they loved and a member of their family and not someone to be dismissed, pushed to the side and taught in isolation. With this new understanding, the issue of inclusion had become, for me, one of caring about every child equally. The child with a disability could and should be a member of my class no matter what their ability. I had begun to approach my teaching from an ethics of caring. Caring for all the children not a select group. To reflect this belief the important question guiding my teaching had become, "Do my practices reflect my beliefs?" I believed that Brian had a right to be in my class with his peers. Therefore, I needed to continuously explore ways to help him become a member of our class.

And Then There Was Susan

After meeting Brian I had grown clearer and firmer in my desire to keep welcoming all children into my class. After a year away from teaching, to study and to do research, I returned to the classroom with a determination to find more opportunity to include students with developmental disabilities in my class. I wanted to be in a space where parents and teachers valued the inclusion of children with disabilities. I often felt alone in my desire to include Brian. This came about when the school in which I taught Brian , opened a segregated class for children with behavior disabilities and my colleagues asked me why I did not request a placement for him in this class. After this situation I realized I needed

to be in a place where other people talked about the issue of inclusion. This change would be necessary to further my understanding of inclusion.

The opportunity to include a child with developmental disability came about in my second year at the new school. Susan, a child with a developmental disability, became a member of the year 1/2 class. Her inclusion resulted from her parents' request for her to come to our school and the school parent advisory group and the principal's knowledge of my desire to have a child with a developmental disability in my class. They had become aware of my interest to do this through our open discussions and reflections on what we meant by a true community.

Parental Support

As the class lists were being prepared for the next year, there was general known edge in the school that a child with a developmental disability was going to be in my class in the fall. Parents were asked to give their preferences as to which class they wanted their child in. One day a parent approached me to say where she wanted her child placed. She began the conversation by saying she understood that a child with a disability would be in my class. As she said it my heart sank. I dreaded her next words. Within seconds my head was flooded with all the negative things that could be said about having a child with a disability in the regular class. The parent continued to speak. I began to prepare my and Susan's defense as to why she should be in our class. As the parent continued, I wondered, if my shock was apparent when she said she wanted her child in my class because she thought that it was important for her child to understand the diverse needs of people in our community. I don't remember what I said, but I do remember the sense of relief that came over me.

Academic Inclusion

Instructions were adapted to ensure that Susan was part of the lesson. For example, in a math lesson on making symmetrical shapes from paper, Susan's goal was to work on her cutting skills and on the concept of same and different, while her peers' goal was to explore the cut and fold method in order to explore symmetrical shapes. During morning message, Susan was required to locate words she was learning while her peers were asked to read the whole message. Susan was assisted in writing by either having me scribe her stories or by dictating to her the letters of the words she wanted in her story.

I found it easy to modify the lessons to accommodate Susan's learning needs. It was always possible to use the existing content and materials in the lessons to meet her needs.

But Will The Children Support My Desire?

When Susan arrived in the fall I was most concerned about how the other children would accept her and help her be part of the class. I was confident that she would progress academically but would the children accept her? As the term progressed, I saw many examples of Susan's peers accepting and supporting her. One day I overheard some of the girls telling a student from another class, "Susan is really neat. She always tells people, 'I LOVE YOU'". On another day a student got Susan a Kleenex because her nose was running without being asked. In math, someone always offers to be her partner. Students make sure she gets to French, music or gym. These examples remind me that all I have to do is model acceptance and the children will take the lead. These observations

have confirmed for me that her presence in the regular year 1/2 class is worthwhile and appropriate.

On The Playground Away From The Teacher's Eyes

In the classroom, Susan was accepted but I was still concerned with her inclusion on the playground. I often observed Susan standing alone watching her peers. I did not see them ask her to join in their play, nor did Susan ask to join in. I struggled with this concern for weeks.

In the beginning, I thought Susan's exclusion resulted from her different play skills than her peers. Susan was very shy in the beginning months and would sit away from her peers in the classroom. However, as the term progressed, she approached her peers more often in the classroom. My worries for her full inclusion changed from 'will the kids like her' to 'how will she learn the necessary play skills to be one of the gang on the playground.' The playground is where friendships are defined. I grappled with "should I expect the kids to include her" in their play. We had a class rule, "You can't say you can't play" borrowed from Paley's (1992) work. But what did that mean when a child did not even ask to play? These questions plagued me for weeks. Susan had been getting more comfortable with her peers in the classroom. Maybe it was time to ask the children for their assistance. I could no longer be silent about how I was feeling. I needed the children's help to solve how to include Susan in the playground play.

Asking For Help

I decided to talk to the children about my concern. When I did this Susan was out of the classroom with the speech therapist. I gathered the children together and said, "I need your help with a concern I have." I gingerly talked about what I had seen on the playground concerning Susan's inclusion in games. I used an example from the day before when I was on supervision. I asked Anna if I could tell the group what I had asked her to do the day before. She knew what I was referring to and quickly said that I had asked her to invite Susan to play with the group. She told us she had asked Susan but Susan had said no. I asked the children why they thought Susan had said no. I drew their attention back to when Susan was first in the class and how she had stayed away from the children. The children labeled Susan as shy. Maybe that was why she had said no to Anna's request. I asked how they thought Susan felt about playing with them. The conversation was filled with caring insight and wonderful suggestions. We talked about changing the rule from "you can't say you can't play" to "you have to say would you like to play". They thought that was a good idea and agreed they would make the effort at recess.

The children were excited about giving their points of view and ideas in order to help me with my concern. However, I felt I needed to ask the children, "If you do not feel like asking Susan to play, is that okay?" I did not want the children to feel I was forcing them to be in a relationship with Susan. The children said no it was up to each of them to decide if they wanted to invite Susan to play. I reassured them that I would honor their desire to participate or not to participate in the plan to ask Susan to play.

As the conversation ended the children shared that the students in the next class did not like Susan. They said the children made fun of her, especially

when her nose ran. We talked about what they thought we should do. I asked if they thought I should talk to this class. They all thought that was a great idea. I asked who would like to come and talk to the other class with me. Quite a few said, "I would." I was overwhelmed by their openness and desire to help me figure it out for Susan.

Putting Their Words To Test

On return from lunch and afternoon recess I was bombarded with stories of how Susan played with the children and how they helped her to participate. The pleasure was not only felt by this group of children but was also felt by Susan. When she came into the classroom she was smiling from ear to ear. This had been a successful day for all. There was a renewed sense of community in our class.

I knew that this was a small step towards the inclusion of Susan as a member of the class on the playground. I knew that the inclusion would require tending to flourish and to grow beyond this day. However, I trusted the children and knew from watching them that friendships would develop, I am hopeful that some will become long lasting ones between Susan and her peers.

Conclusion

Listening and writing to each of my participants, it became evident that there were themes interwoven throughout the stories of Percy, Herb and myself. For all of us, our stories were about the construction of identity. This research has provided a space for Herb and Percy to tell their stories but has also grown to be a space for my reflections as a teacher. The research process was a telling

of my teacher's story. Percy's and Herb's words became a mirror for reflection of my lived experience in the special education classroom. Their words have become part of the education of this teacher.

Percy's and Herb's words make me wonder how can I create, in my future classrooms, an adhocratic environment (Skrtic, 1991) where students are encouraged to participate openly, to discuss their own lived experiences and to develop their own voices with their peers and teacher. To do this, I must challenge myself to continue to discover my own biases and limitations and to become aware of the impact of these on my teaching. I must develop a knowledge of, and sensitivity to, times when I am not listening and to understand the influence of this on the learning in my classroom.

To further enhance my own learning I will need to seek places where a dialogue method is used to create an effective democratic learning environment (Darder, 1991). The experience at McGill started the process through the "... dialectical relationship between the student as an individual and a social agent..." (Darder, 1991, p.140). To continue to be attentive to how my personal ethics relate to the instruction in my teaching I will need to remind myself that I do have a personal and social responsibility to speak out and ensure that children with disabilities are not excluded from education along side their peers.

When I first I reviewed the literature I was shocked to discover that the thoughts of including children with developmental disabilities with their non-disabled peers has been in the literature for some time (Neisworth & Madle, 1975, Blatt, Biklen, & Bogdan, 1977). I was involved in teacher education in the early 1980's but have no memory of discussions that talked about children being educated in this way. Sarason and Doris referred to in Zigler & Muenchow (1979) pointed out, "although public policy now calls for placing handicapped children in the least restrictive environment, teacher training centers continue to

educate school personnel in the tradition of the most restrictive alternative" (p. 994). My education training was reflective of this.

Since the awakening I experienced at McGill, I have thought about and have been reminded by Percy and Herb of my responsibility as a teacher to focus on the accepting relationships between student's with and without disabilities. I have worked towards creating these relationships. For Bogdan and Taylor (1990) an accepting relationship is;

> ... one between a person with a deviant attribute and another person, which is a long duration and characterized by closeness and affection and in which the deviant attribute (e.g. disability) does not have a stigmatizing, or morally discrediting, character. Accepting relationships are not based on a denial of differences but rather on the absence of impugning the different person's moral character because of variation (p. 191).

I believe the focus on the sociology of deviance and rejection has been more prevalent in my understanding of people with developmental disabilities. This is reflective of the questions I have been asked and focused on in my research and teaching. To make a difference for students with disabilities I believe it will be incumbent upon me in my teaching to be attentive to how acceptance is accomplished. To do this it will be necessary to work in classrooms where a more diverse group of children are welcomed. It is the positive examples now that I believe will further expand my understanding of my role as a teacher in creating spaces for children not to experience what Percy and Herb were made to endure.

Bibliography

Alberta Teachers' Association. (1993) . *Trying To Teach: Interim Report of the Committee on Public Education and Professional Practices.* Edmonton, Alberta: Author .

Allport , Gordon W. (1954). *The Nature of Prejudice.* Toronto: Addison-Wesley Publishing .

Apter, S. J. (1977). *The Public School.* In R. Blatt, D. Biklen & R. Bogdan (Eds.), An Alternative Textbook in Special Education. (pp. 105-126). Denver: Love Publishing.

Atkinson, D. , & Williams, F. (Eds.). (1990). *Know Me As I Am: An Anthology of Prose, Poetry And Art By People With Learning Difficulties.* Toronto: Hodder & Strughter.

Ascher, C. (1988). *Grade Retention: Making the Decision.* Eric/Cue Digest 46

Asher, R. M., & Fine, G. A. (1991). *Fragile Ties: Shaping Research Relationships With Women Married to Alcoholics.* In W. B. Schaffir & R. A. Stebbins (Eds.). *Experiencing Fieldwork: An Inside View of Qualitative Research* (pp. 196 - 205). California: Sage Publications.

Barreca, R. (1991). *They Use To Call Me Snow White But I Drifted.* New York: Penguin Books.

Becker, Howard S. (1963). *Outsiders: Studies in the Sociology of Deviance.* New York: Free Press.

Belenky, Mary Field, Clinchy, Blythe McVicker, Goldberger, Nancy Rule, & Tarule, Jill Mattuck. (1986). *Women's Way of Knowing.* New York: Basic Books.

Berliner, D. & Casanova, U. (1986). *Do Failing Students Benefit from being Retained?* Instructor, 95 (8) 14 - 15.

Biklen, Douglas. (1992). *Schooling Without Labels.* Philadelphia: Temple University Press.

Blatt, R., Biklen, D., & Bogdan, R. (1977). *An Alternative Textbook in Special Education.* Denver: Love Publishing.

Bogdan, R., & Taylor, S. J. (1982). I*nside Out: The Social Meaning of Mental Retardation.* Toronto: University of Toronto Press.

Bogdan, R., & Taylor, S. J. (1987). *Toward a Sociology of Acceptance: The Other Side of The Study of Deviance.* Social Policy, 18(2), 34-39.

Bogdan, R., & Taylor, S. J. (1989). *Relationships with Severely Disabled People: The Social Construction of Humanness.* Social Problems, 36(2), 135-148.

Bogdan, R., & Taylor, S. J. (1990). *Looking at the Bright Side: A Positive Approach to Qualitative Policy and Evaluation Research.* Qualitative Sociology. 13 (2), 183-192.

Brillat - Savarin (1985). *The Physiology of Taste.* (M.F.K. Fisher, Trans.). San Francisco: North Point Press. (Original work published in 1825).

Brown, Lyn, Mikel & Gilligan, Carol. (1992). *Meeting at the Crossroads.* Cambridge: Harvard University Press.

Bruner, J. (1986). *Actual Minds, Possible Worlds.* Cambridge: Harvard University Press.

Clandinin, D. J. (1986). *Classroom Practice: Teacher Images in Action.* London: Falmer Press .

Connelly, F. M. & Clandinin, D. J. (1994). *Telling Teaching Stories.* Teacher Education Quarterly, 21, 145 - 158.

Clandinin, D. J. & Connelly, F. M. (1994). *Personal Experience Methods.* In N. Denzin & Y. Lincoln (Eds.), Handbook of Qualitative Methods . San Fransico: Sage .

Coles, R. (1989). *The Moral Life of Children.* Boston: The Alantic Monthly Press .

Connelly, F. M., & Clandinin, D. J. (1988). *Teachers as Curriculum Planners: Narrative of Experience.* Toronto: OISE Press .

Connelly, F. M., & Clandinin, D. J. (1990). *Stories of Experience and Narrative Inquiry.* Educational Research, 19(5) , 2-14.

Crites, Stephen. (1986). *Storytime: Recollecting the Past and Projecting the Future.* In T. R. Sarbin (Ed.). *Narrative Psychology: The Storied Nature of Human Conduct* (pp. 152-173). New York: Praeger .

Darder, Antonia. (1991). *Culture and Power in the Classroom.* Westport: Bergin & Garvey .

Dawson, Peg, Rafoth, Mary Ann & Carey, Karen. (1983). *Supporting Paper on Relention: Position Statement for National Association of School Psychologists.* Washington: NASP Children's Services Committee.

Davies, A., Hogan, P., & Dalton, B. (1993). *Journals: The Conversations of Practice.* In J. Clandinin, A. Davies, P. Hogan, & B. Kennard (Eds.). *Learning to Teach: Teaching to Learn* (pp. 51-63). New York: Teachers College Press.

Duerk, Judith. (1989). *Circle of Stones: Woman's Journey To Herself.* San Diego: Lura Media.

Edgerton, R. B. (1967). *The Cloak of Competence.* Berkeley: University of California Press.

Elliott, Olive. (1987, November). *Face it - A Few Children Might Be Impossible to Educate.* The Edmonton Journal, pp. A13.

Elliott, Olive. (1987, November). *Limiting Access to Education Reflects Fiscal Realities.* The Edmonton Journal, pp. C1.

Freire, P. (1970). *Pedagogy of the Oppressed.* New York: Herder and Herder.

Frye, J. S. (1986). *Living Stories, Telling Lives* . Ann Arbour: The University of Michigan Press.

Fushs, D. & Fushs, L. S. (1994). *Sometimes Separate is Better.* Educational Leadership, 52(4) pp 22 - 26.

Gallmeier, C. J. (1991). *Leaving, Revisiting and Staying in Touch: Neglected Issues in Field Research.* In W. B. Schaffir & R. A. Stebbins (Eds.), *Experiencing Fieldwork: An Inside View of Qualitative Research* (pp. 224 -231). California: Sage Publications .

Gartner, A. (1988). *Parents No Longer Excluded, Just Ignored.* Exceptional Parent. 18(1), 40-41.

Gergen, K. J., & Gergen, M. (1986). *Narrative Form and the Construction of Psychological Science.* In T. R. Sarbin (Ed.). *Narrative Psychology: The Storied Nature of Human Conduct* (pp . 22 - 44) . New York: Praeger.

Gilligan, C. (1982). *In a Different Voice: Psychological Theory and Women's Development.* Cambridge: Harvard University Press .

Goffman, Erving. (1963). *Stigma: Notes on the Management of Spoiled Identity.* Englewood Cliffs: Prentice Hall .

Goldberg, N. (1986). *Writing Down the Bones.* Boston: Shambhala.

Hahn, Harlan. (1989). *The Politics of Special Education.* In Dorthy Kerzner Lipsky & Alan Gartner. (Eds.), *Beyond Separate Education: Quality Education for All* (pp. 225- 242). Baltimare: Paul Brookes Publishing .

Heilbrun, C. (1988). *Writing a Women's Life.* New York: Ballantine .

Hogan, P., & Flather, C. (1993). *Finding Voice, Finding Place.* In J. Clandinin, A. Davies, P. Hogan, & B. Kennard (Eds.), *Learning to Teach: Teaching to Learn* (pp. 100-108). New York: Teachers College Press.

Hollingsworth, S. (1990). *Learning to Teach through Collaborative Conversation. A feminist Approach.* American Educational Research Journal, 28(2). 373-404 .

hooks, bell. (1992). *Black Looks: Race and Representation.* Toronto: Between the Lines .

Jordan, T. E. (1972). *Third Edition: The Mentally Retarded.* Columbus: Charles E. Merill.

Kidder, Tracy. (1989). *Among School Children.* New York: Avon Books.

Kim, Hyo-Jung. (1991). *Do You Have Eyelashes?* In C. Gilligan, A. G. Rogers, & D. L. Tolman (Eds.), *Women Girls & Psychotherapy: Reframing Resistance* (pp. 201-211). Binghamton: Harrington Park.

Kirby, S. L. & McKenna, K. (1989). *Experience, Research, Social Change: Methods From The Margins.* Toronto: Garamond Press.

Koegel, R. L., Rincover, A., & Egel, A. L. (1982). *Educating and Understanding Autistic Children.* San Diego: College-Hill Press.

Le Guin, U. K. (1989). *Dancing At the Edge of the World: Thoughts On Words, Women, pPaces.* New York: Harper & Row.

Lipsky, Dorothy Kerzner, & Gartner, Alan. (1989). *Beyond Separate Education: Quality Education for All.* Toronto: Paul Brooks.

Lourde, Audre. (1984). *Sister Outsider.* New York: The Crossing Press.

Lundy, Marion Dobbert. (1982). *Ethnographic Research: Theory and Application for Modern Schools and Societies.* New York: Praeger.

Malker, A. (1991). *Imagine History: "A Good Story and a Well-Formed Argument ."* In C. Witherell & N. Noddings (Eds.), *Stories Lives Tell: Narrative and Dialogue in Education* (pp. 29-47). New York: Longman.

Martha (Speaker). (1993). *Blue is the Color of Hope* (Cassette Recording). Toronto, Canada: Ideas CBC - Radio.

Miller, J. L. (1992). *Teacher's Space: A Personal Evolution of Teacher Lore.* In William Schubert & William Ayers. (Eds.). *Teacher Lore: Learning From Our Experiences.* New York: Longman .

Miller, Ron. (1990). *What Are Schools For? Holistic Education in American Culture.* Vermount: Holistic Education Press.

Neisworth, J. & Madle, R. (1975). *Normalized Day Care: A Philosophy and Approach to Integrating Exceptional and Normal Children.* Child Care Quarterly, 4 (3), pp 163-171 .

Noddings, Nel. (1984). *Caring :A Femine Approach to Ethics and Moral Education.* Berkely: University of California Press.

Oakley, A. (1981). *Interviewing Women: A Contradiction in Terms.* In H. Roberts, (Ed), *Doing Feminist Research* (pp. 30-61). London: Routledge & Kegan Press.

O'Brien, J. & O'Brien, C. Lyle. (1991). *Members of Each Other: Perspective on Social Support for People with Severe Disabilities.* Syracuse: The Centre on Human Policy University of Syracuse for the Research & Training Center on Community Living.

Paley, Vivian Gussin. (1992). *You Can't Say You Can't Play.* Cambridge: Harvard University Press.

Peskin, A. (1988). *In Search of Subjectivity - One's Own.* Educational Researcher, 17(7), 17-21 .

Pieper, Elizabeth, (undated). *Sticks and Stones: The Story of Loving a Child.* Syracuse: Human Policy Press.

Purkey, W. W. & Novak, J. M. (1984). *Inviting School Success.* Belmont: Wadsworth Publishing

Robinson, J. A. & Hawpe, L. (1986). *Narrative Thinking as a Heuristic Process.* In T. R. Sarbin, (Ed.), *Narrative Psychology: The Storied Nature of Human Conduct*, (pp. 111- 25). New York: Praeger.

Rosenthal, R. & Jacobson, L. (1968). *Pygmalion in the Classroom: Teacher Expectation and Pupil's Intellectual Ability.* New York: Holt, Rinehact & Winston.

Sarason, Seymour B. (1982). *The Culture of the School and the Problem of Change.* Toronto: Allyn and Bacon.

Sarason, Seymour B . & Doris , John . (1979) . Educational Handicap, Public Policy, and Social History . New York: The Free Press .

Sarbin, T. R. (1986). *The Narrative as a Root Methphor for Psychology.* In T. R. Sarbin, (Ed.). *Narrative Psychology: The Storied Nature of Human Conduct* (pp. 3-21). New York: Praeger.

Savage, F. (1992). *Reclaiming Our Professionalism - Part II.* The ATA Magazine, 73(1) 47.

Schon, D. A. (1983). *The Reflective Practitioner: How Professionals Think In Action.* New York: The Basic Books.

Schon, D. A. (1987). *Educating the Reflective Practitioner.* London: Jossy-Bass.

Sewall, I. (1992). *Personal Communication.*

Shanker, A. (1994). *Full Inclusion is Neither Free nor Appropriate.* Educational Leadership. 52(4), pp 18 - 22.

Shogan, Debra. (1988). *Care and Moral Motivation.* Toronto: OISE Press.

Skrtic, Thomas, M. (1991). Behind Special Education. Denver: Love Publishing.

Snell, M. E. (1978). *Systematic Instruction of the Moderately and Severely Handicapped.* Columbus: Charles E. Merrill.

Stebbins, R. A. (1991). *Do We Ever Leave the Field? Notes on Secondary Fieldwork Involvements.* In W. B. Schaffir & R. A. Stebbins, R. A. (Eds.), *Experiencing Fieldwork: An Inside View of Qualitative Research* (pp. 248 - 255). California: Sage Publications .

Taylor, S. J. (1991). *Leaving the Field: Research Relationships and Responsibility.* In W. B. Schaffir & R. A. Stebbins (Eds.), *Experiencing Fieldwork: An Inside View of Qualitative Research* (pp. 238-247). California: Sage Publications .

Taylor, S. J. & Bogdan, Robert. (1989). *On Accepting Relationships between People with Mental Retardation and Non-disabled People: Towards An Understanding of Acceptance.* Disability, Handicap & Society. 4(1), 21- 36.

Uditsky, B. (1993). *From Integration to Inclusion: The Canadian Experience.* In Roger Slee (Ed.), *Is There a Desk With My Name on It?* Washington: The Falmer Press.

Wolfensberger, W. (1972). *Normalization.* Toronto: Leonard Crainford.

Wolfensberger, W. & Thomas, S. (1983). *PASSING (Program Analysis of Service Systems' Implementation of Normalization Goals): Normalization*

Criteria and Ratings Manual. (2nd ed.). Toronto: National Institute on Mental Retardation.

Witherell, C. & Noddings, N. (Eds.). (1991). *Stories Lives Tell: Narrative and Dialogue in Education.* New York: Longman.

Zigler, E. & Muenchow, S. (1979). *Mainstreaming :The Proof Is in the Implementation.* American Psychologist, 34 (10), 993-996.

APPENDIX A

Sample Of Conversation Transcripts From A Conversation With Herb

H.R. One of the things that came up as I was going through what we chatted about the last time was I wondered if you have any memory of being tested?

H. Yeah.

H.R. Can you tell me some of that? What it felt like? What it was like?

H. Yeah ... ah... ah.... the testing to well .... they they ah.. they didn't make it look like scary. Like they made you feel, they made you feel comfortable but ah.. the testing was it was done. I remember ah... going to a hospital. I think it was a hospital, a hospital or ah a University. No it was a University, a college. Ah when they, yeah it was the University in Calgary. I was tested like ah.. they show you ah you did blocks. Then you did puzzles. They show you ah picture of scattered art and they ask you what you thought that picture was. And ah ah to me it was... to me it didn't bother me.. but you know ah in a way I guess it was just for them to find out what my high Q was or my low Q. I don't think that they were meaning to hurt me or test me, they were just trying to figure out where I belonged. And even though I passed them with flying colors. But you know they .. they didn't really get to spelling or math. You know they didn't test my skills with that.

H.R. No.

H. No.

H.R. Any time in school did they do any any more formal kind of testing?

H. Yeah they did. Yeah what I was going to say at St. Anthony, one day a week, I was I was meeting with this lady. I guess she was a volunteer person but she sat down with me. That is when they decided that grade six was too hard for me and I wasn't getting no where. That is when they sent me to Marie Rose school. Which that was again I wasted a year.

H.R. How did it feel when they made that decision?

H. It was scary. It was ah.. you know I knew I wasn't going to get nothing out of it. You know... you probably feel the same way as I did. When you just learn something you've been taught, you've been taught all your school years you get to a point that your just tired. That is the way I felt. Like you know.. Marie Rose school. Every afternoon, or every morning we had to watch Sesame Street. Like ah, there were better things you know. I think the teachers were at wrong. You know I think that they kind of took me and this other person that had a little more high capacity for learning. If they took just time from Sesame Street and taught us math or spelling. And ah it was was really frustration because at that time I didn't what my right were and ah that is why I got involved in People First because I didn't know what the school education was. I know .. back them that these people that these people had a right ... like ah if I know, if I known that I could took those. If I had know I could have taken these teachers to the

school board and say this is what they are teaching us, you know, you know why I am doing this for you Heather is I don't want other students to go through what I did.

H.R. I agree. I think people have to hear this. And we don't go to the people who have been through the system and ask them to tell us what it was like.

H. That is right. What I would like to do give this tape to somebody that is in high school and wants to quit school. And see how they and see how they you know. My IQ is you need an education to make it in this world. If you don't you will be doing dishes for the rest of your life. And for what. Because you wanted to go and have fun instead of learn.

H.R. But in your situation that is not, that doesn't fit for you because you wanted an education

H. No. I wanted an education and I couldn't do nothing.

H.R. Do you have any sense of when they decided that grade six was too much and you were going to go to this school that was for children labeled mentally handicapped? Can you conjure up moments when that happened? Can you remember the discussion around it or any of those pieces?

H. I remember they sat down with me and they told me that they were going to move me. Ah ...at that time I was a safety patrol. And ah the grade

five teacher, he was in charge of the safety patrol. And ah... wh..what really hurt me was I had to step down from being a safety patrol. That, learning that I had to leave that school and ah.. leave safety patrol, it was hard. Going to that school, like I said, I wasted a year. I would have rather been working. You know, and there were times that I was just ready to walk out of that school. Cause it was just frustration for me. And ah what really shocked me was one time I went home and ...what really.. I wasn't even a safety patrol for a long time. But ah .. my sister came and said you won the trophy. I said what do you mean the trophy? She said well you won, you won the top patrol trophy. ...yeah. I went to St. Anthony's and they awarded me with this trophy and a crest. I was top boy patrol for 75-76.

H.R. You had already been moved to the other school?

H. I had already moved to the other school. They did this through the year. they didn't wait until September.

H.R. How did it feel to go back to the school to get this award?

H. The award was ... was something that they knew that I could do and I deserved it. And the guy, the teacher that gived it to me was the one that if he had the time he would have probably quit his job and took time to teach me. That was my ah.. that was just a reaction that I got from him. Like ah he was a grade five teacher and when we moved. Like not too many. You don't hear this to often when a class actually throws a going away party for one of their classmates. Well the teacher was my sisters

grade five teacher when they heard that we were moving they had a going away party for her. And he was you know he was just that type of teacher that he would do something. And ah, like receiving that reward to me I knew I deserved it. I was one of the top, I was one of the top patrols. I was always on time. And ah.. the way I looked at it I deserved it. I deserved it. I worked for it. I contributed to it. Sure there were other patrols that were there for the whole year but when I left I figured you know. It just felt that I was going to win that trophy. .....

H.R. It is interesting that they would do that after you had left. It shows that you had done a really good job and you weren't ever there and they remembered that you were that good at what you were doing.

H. Yeah....Yeah....Yeah. and ah I actually sat down with my mom and dad and I asked them I said you know did the grade the one teacher say anything to you? And you know there's again now, now parents. I don't know today but more parents have more research. They have a say in what goes on.

H.R. Your parents were the same as you. They didn't know what voice they could have.

H. That is right.

H.R. It wasn't your parents fault. It was the way that they were made to feel; In terms of their right to question.

H. So with grade one even though I was slow she failed me. And then I went to ... Calgary. In Calgary two and three. ...Yeah two and three. ....And Ardrie was four and five. ...And then nope nope pardon me, ...Ardrie was three, three and four. ....And then ah .... and Rockfort was five. And then moved back to Calgary - Forest Lawn. And that was that was grade six. Five and six. And that was when they moved me again to this other school where they were I knew I wasn't getting nowhere made excuses and I was sick. And to me to me.. I was just .. I think at that stage it just got to me I wasn't getting no where so I just lost interest in school.

H.R. Why bother.

H. Why bother yeah. You go every day to the same class and you are learning the same thing over and over. And ah your not.. to me going to that school where every morning you were doing the same thing over and over. It wasn't getting me no where. You to get me something or get me interested in another program but don't keep me in one place. And ah then from there we moved to ... where did we move. Oh yeah Drumheller That is when I went to Mario Rose school. I was in grade six.

H.R. That was in Drumheller. So when you were in Calgary they put you in a different school. They put you in a special school.

H. Yeah It was just a class. It was mixed in.

H.R. In Drumheller you started in a regular class then they moved you out.

H. Yeah.

H.R. When you were chatting with your parents how did they feel going down this memory lane with you remembering what school was like?

H. They know what I went through. And ah you know, there were a lot of times that they were ready to pull me out because they knew I wasn't getting nothing out of it.

H.R. Especially in the Mario Rose school.

H. Yeah... but I'm, I'm a person who tries to get along with everyone. You know even though, even though I you know even though what those teachers did to me. There is a part of me that hates them for what they did. But there is another person saying it is not my fault it is their fault. They needed help. Because you know I don't think they really had. I know for sure that they didn't have a teacher degree. I think that it was, well maybe Joyce but Sharon. I don't think that Sharon I don't think that Sharon had the didn't go to college for three years to be a teacher. Joyce yes but you know they, they didn't know how to to work with us. And ah.. yeah but other wise if I had to do it again I would ah I would try my best in getting a better education that what I got.

H.R. But the last time we talked you had said you sort of felt like it was your fault. You had that sense of it being your fault. What did it feel like? What made you think it was your fault? Like even now your saying to me if you

had it to do over again I'd get a good, get a better education. What would you do?

H. I know where I can stand now and speak my mind.

H.R. Tell me how you would do that.

H. Like if I was, if I was going to go tomorrow to that same school in Calgary and see that teacher and she is probably going to say why didn't you attend school? I would tell he why. I lost interest. You know, I was I was given the same thing over and over you know. You get a job where you do something over and over and over eventually you are going to get sick of it. And you know to me going to that school was okay, they are giving me the same stuff over and over. I want to learn something new. You know and ah didn't change. Why should I please them when they if they aren't please what I want.

H.R. It is a good point. When you tell me this story it makes me think about what I did in special education. I was that teacher that you are talking about. I think about a boy and his program was the same day in and day out. And his mother use to complain how bored he was. And I didn't do a very good job thinking about what she said. I think I am a caring person but it took me a long time to recognize that in special education that programming like what you had could happen. We don't believe that you can learn so we just get into a rut and do the same thing over and over again.

H. The same thing with Mario Rose school you know watching Sesame Street. Every day you just get you get just tired. And even though I wanted to keep myself busy doing math or something. To me it was rest time for the teachers. And you know just picturing back what they did was like. I'm glad they closed that school down. And that what really and that is what you know. Even though I sit on the board of the Red Deer association. I can see from my point going back to my education, like why aren't these students being mixed with the regular school? You know. How can you wake up people and say look it. Sit in their seat. Be in their position. I had a room mate that had a limp hand and a foot that he had to drag and people looked at him. And one time his mother said don't talk to him he is handicapped. And I said excuse me he has a mind of his own. He maybe handicapped disabled handicapped but said he has a mind of his own. He can do something that you probably can't do. I said picture yourself in his shoes. You know, when I go to these speeches like I tell people before or after you know, even though you look at a handicap and you feel sorry or your afraid to make a or even talk to him or feel sorry for him or ah some people are today they ah they look at a handicap and just figure that he should be put away. And I always tell the people you know now :s the time to help us get what we want. Because I said to them you hear in the news you hear in the papers I say to them you can even walk out in the street that you can get hit by a car and wake up in the hospital. And then you mad because the help is not there. Get the help now if it does I don't want it to happen if it does happen to you ... you know that there is places that will help you. That is what the people have to wake up. There was guy that was in that was in oil rig. And he he always put down the handicapped people and he didn't want nothing to do with the

handicap or you know he figured they should be in place but when he ended up in a wheelchair his attitude just changed like I'm a handicapped now. You know..

H.R. It made it real for him.

H. Yeah, and awareness week is coming and the programs you know the programs I figure that they should is have a rally where somebody put cloth between somebody's eyes or put a mask and have then walk a day being blind. Or have a normal person that is you know that is not handicap put them in wheelchairs have them wheel around in wheelchairs and take them to places where handicap people have problems. Or they want ah .. you know.. what I would love to do is get these people that drive into the handicap parking and have them have to get wheelchair in the parking lot and wheel into some building.

H.R. And see how difficult that is.

H. See how difficulty it is. You know.

H.R. In terms of what you were talking about, the segregated school in Red Deer have you ever been in the school? Have you ever gone there?

H. To Parkland? Yes I have.

H.R. What kind of things does it make you think about?

H. Your closed down in the world.

H.R. Say that again.

H. You're closed out. You are in your own group. And ah... what ...what I think is they should be mixed in with everybody else. Even though they may be slow or you know they might be smart in something. You got to remember we are all handicapped.

H.R. Has there ever been any discussion about that school? You know you sit on that board.

H. Some times teachers asking for raise or ah and ah.. talking about teachers getting raises. Even hearing today you hear teachers are getting raises but ah that to me that is what the teacher is worried about these days. They aren't worried about teaching. They get that pay checks.

H.R. The board doesn't talk about the philosophy, the values what is happening with the children in the school?

H. No. ... I can picture. You know. Like going into that school is like Marie Rose school. Really closed out and not going and getting involved with the other regular classroom. When I was going to special schools even though we were in trailers at recess we were mixed with the children or ah other activities were mixed with the children. But we were in a different part of town like Marie Rose School.

H.R. You couldn't even have those kind of opportunities of being with other kids.

H. No.

H.R. That is the extreme being totally excluded. The last time you shared that the teachers didn't have time for you. that you felt that they didn't have time. How did you make sense of that in term of how the teachers made you feel when you had difficulty. What did it feel like. You said it I'm trying to get a clear picture about what that looked like to you as student a teacher not having time for you?

H. Umm.... The way I look at it is umm.. you know ... again it was like today's society and that is what I want to do you know you hear you hear teachers wanting a raise. But do they really deserve that raise. Are they teaching their students? You know that scares me. Like even though, even though what I'm trying to prove is what I'm trying to do is I don't want another person to have the education that I didn't have.

H.R. Do you think right now that there are students experiencing the same thing that you are experiencing today?

H. I do say so, yeah.

APPENDIX B

Sample Of Conversation Transcripts From A Conversation With Percy

P. I'll start off with segregation in terms of being in the educational system. It has been very devastating spiritually. To grow spiritually, confidently wise and have a voice. Even now as I talk I can feel the emotions arise.

H. I can hear it is your voice, it has changed. We said, I know we said before that this will be painful. I think not only painful for you but painful for me because I think you will bring up things that I need to think about in myself.

P. The key factor is I disagree with segregation and always round as one that has experienced it. It's been a very negative experience. There are many reasons why I'm against segregation. I'll just name a few and we can discuss further. As things come up in our further discussions that we are going to come forth.

I am very angry at the ... I have to leave my anger with the bureaucrats because they are the ones that are the decision policy making people. In terms when I was younger I was very angry at instructors because the impact and the way I was treated when I was younger.

I didn't have the understanding. It was from a kid child's point of view and years ago, yes I was angry at the teachers because you know in a kids mind that's what you see.

You resent the person that is teaching you because you are not being heard. And today I'm not angry with the teachers because I can see it really lies with the bureaucrats.

H. Because you take an adult perspective?

P. Yeah. I'll guess I will start with speaking from the child in me because we all have a child in us.

H. Uhhuh...

P. When I was younger I hated the school system because in terms of our programs being set up we weren't acknowledged. My foster parents tried to talk to various teachers. I will not name them because it isn't fair.

The teachers treated them, "Yes you'll be heard. We have to pretend we are listening but don't. Just do what we think is best." In terms of, I remember going to a meeting because my foster mother saw that I wasn't being heard and she saw that even at home how upsetting it was for me. Each day I'd come home and I never wanted to go to school. I even played hooky. I made up lies because I didn't want to go to school. I hated school. And then those days I didn't know how to express "I am angry." All that I knew was that I was in a black hole with no way out. How do I get out? Is it my fault because I felt I was to blame because I was a bad person because of my disability. I really felt that I shouldn't be heard. It was confusing to me.

Because my foster mother would keep saying to me, "It is not your fault." I was very confused.

I was getting mixed messages. I hated being in a segregated atmosphere because I was always being teased, challenged, picked-on, thrown in the mud. I get thrown into the showers.

There was an instructor in the classroom where I wanted to ask a question but at that time I was a very nervous and insecure child and it didn't come out right because it sounded funny to them. The teacher laughed at me. Literally said, "She's retarded. Don't listen to her." That really hurt. Then afterwards it was recess time and I wanted to go and talk to the instructor. I over heard that instructor saying to the other teachers, "Well, we've got to program things for them. They can't think for themselves." I really felt devastated. That's when I went home and I told my mother that I wanted to kill myself because that's how bad it was for me.

H. It must have been hard to go back everyday?

P. I never liked school when I was younger and I did poor. I always had poor marks in school. I was forever failing subjects. I didn't care about school because of all these feelings and I didn't know how to deal with them. I would just build a wall around and I went only because I had to go, I had no voice. I was just a thing.

H. This is bringing up so much pain.

P. This was the reality. I would never want anybody to go through that. It's awful. There was one instructor I hated so much.

H. When you started school did you start in a regular classroom?

P. NO!

H. You went right into special education?

P. Yes! That was a decision the government made.

H. When you were just a little girl?

P. Yes, because they saw the disability and right away bang!

H. They put you into a segregated school?

P. And then I ended up going to Michener and from there back into a segregated classroom.

H. Most of your schooling has been in a segregated classroom?

P. Most of it, except when I was in grade 11. Then I went into a regular school, and that is when I started to pick up.

H. That's interesting.

P. 'm not really picking up. But my social skills started to pick -up. I felt when I was in a segregated classroom my social skills were effected because I was never taught group interaction, one-to-one interaction. I didn't know. It was that bad. I didn't even know how to cross the street. That's how bad they had the control on me because things were always done for me. The teachers always did it for me and when I came face-to-face with it I didn't know what to do with it.

I was too scared to trust my own judgment because that's what segregation did. It took my own belief away. My social skills were effected. I didn't know how to interact and in terms of seeing all the other kids in regular classrooms we were not taught the ideas that they do now a days in terms of approaching someone to be a friend. to work lets say for example homework. We were never given homework.

H. I'm sure seeing Crystal going through school reminds you of all the things that happened to you in school?

P. At times it does, and I think that is why I push her away because it is still in me.

H. It is painful for you. There is so much unresolved pain. ... Do you remember any of your lessons? What did you do in school?

P. What did we do?

H. Yeah. Do you have any memory of what a day was like?

P. When we went to school, right away the instructor would start. I remember vividly standing there and looking at us as if.. Then she would say we are going to do this and this today and she wouldn't explain why. That's one thing I missed. Usually in school it should be explained we are going to learn this because why blah blah, but that was never done. We were always given easy stuff like 1+1. They took us on a lot of field trips. I remember that but they didn't teach us really anything about history, mathematics. If they did focus on math it was the easy stuff. Like I said 1+1.

H. Considering you have an accounting background. Imagine what you could have learned if they thought you could learn?

P. And yeah it was all easy stuff. In terms of science all we did was go outside and look at the trees. We weren't given any specific reason why we were looking at the trees, What for? I remember that. I was told to go sit by a tree and look at the tree. But I remember that. And if we were given directions it was a direction of the teacher. If we wanted to know why it wasn't explained. We were humored. She'd say something else. I remember asking why we were going on this field trip to the zoo. She said don't you want to see the animals? I said but I want to know why. You should understand I'm doing this trip for you, you'll like the animals.

I wanted to go learn to drive a car for an example when I was fourteen because my brother stared showing me and we had. We were put into a class in the regional high school. I remember very vividly what happened.

We were asked what we wanted and I said... We were told we would be taught cooking. That was fine and that we would be taught how to do things like laundry. Things for everyday life. That classroom was specially called the EMR room which was the experience mastery room and the goal was for the instructors to teach us everyday living skills. Then she asked us what do you people want? I said, "I would like to learn how to drive. My brother is teaching me. I don't mind learning to cook because I already do started at temp cooking. That's what I want to do." "NO! You don't drive a car. You are too young to drive a car. That's not appropriate P. Because that's not everyday living."

H. What does she think everyday living is?

P. Yeah and then someone else said, "We want to learn science." Other people said we want this and we want that. Some of the things she agreed with, the ones only she wanted. What she thought best for us. Like the cooking. It was when we suppose to learning social studies. It was again Mickey Mouse stuff. She went as far as saying describe the St. Paul area. I said I went to somebody because I didn't have the guts or courage and I started whispering, "Why don't we learn the cities and the capitals like other students." So I went and tried to be heard through someone else. I knew it was the cowards way then but I didn't have the confidence.

H. You were a girl. Lots of girls are like that. I had similar experiences not having the confidence to tell teachers what I thought.

P. In terms it was basically Mickey Mouse stuff. I saw that segregation not really to me anyway we were set aside and I felt ---- in terms of my being segregated that we were different and that has stayed with me forever. And that we were a bunch of retards. I hate that word but I have to use the word in this instance. I'm using it because that was the past and that is the way it was. I was not heard.

H. You went to New Hope School?

P. Yes

H. Was that where most of your schooling was?

P. I had two years of New Hope School.

H. That's on the same ground as the other school?

P. Yeah.

H. What was it like in terms of the other children?

P. I hated it there. Again it was segregation. When I came out of Michener Centre I went to New Hope.

H. When you lived at Michener center you were a child?

P. I was a child at a very young age. I won't go much into Michener because we are talking about education. I went to New Hope after coming back from that inhumane jail. Because that's what I thought about Michener.

H. Did you go to school while you were at Michener?

P. No.

H. No schooling while you were there for 1 1/2 years. How old were you?

P. I was five.

H. So you had no school when you were five and six. I wonder how the institution could get away without providing you an education while you were there.

P. I don't know but I would like to see my child personal file. I am going to do that. I am in the process already of setting up an appointment. But they are telling me that I can't see the file. Only sections and they are asking me why do I want to view my file. Is it for illness in the family?

H. Were you a ward of the court?

P. Yeah. I was a ward. That is how come the government was able to do what they did.

H. So was New Hope your first school experience?

P. Yeah.

H. So what was it like when you spent those two years there?

P. I was. When I went there I didn't have no minor of capabilities to think. Because of being in Michener. That really set me back. All that I can remember was in a black world. with no sense of being able to think. I couldn't even write my name. It took at least six months according to my foster mother to write my name. When I would take a pencil I would always shake. I didn't have. At that time I didn't have thinking capacity. To connect things when people are trying to teach me. That's how black it was, I can just say black. Because that was what it was like to me, black. Nothing, I would just sit there at New Hope and rock. Because that was a learned behavior from the inhumane jail Michener. I could remember about being in New Hope because I was a very nervous child. I would wet my pants. I remember my hair getting pulled for that and saying that's bad don't you know where the washroom is? Although, I remember the teacher working with me for about an hour a day trying to teach me how to write my name. But even as young as I was I knew that it was segregation. Because I would see all the other kids go into the other school. I knew what they were. And again that feeling of isolation was reinforced again.

H. Was there ever any interaction between the kids in the other school and your school?

P. NO. There was no interaction. We were given recess but we were told to stick with ourselves. To play with one and other.

H. The two schools were really close to each other on the school grounds aren't they?

P. Yeah. There is a big building and at that time it was for the grade 7 to 9 at that time. In terms of interacting with the students from the other school we were told to stay on the ground of New Hope.

H. Did you have recess at the same time?

P. At different time. At the odd time and the schedule had to be rescheduled we would sometimes end up having recess at the same time. We would see the other kids and I remember standing by the wall and wishing that I could be over there. I wished I could go and play those games with them. That's what I was thinking and one time I did take off. I went.

H. You weren't so quiet that time and unassuming?

P. Occasionally times I wasn't.

H. What did you do when you ran away?

P. I ran to the other school and I just stood there. I didn't have the guts to ask can I play with you kids. I just stood there and watched them. They

were very cruel. They said to me "go back you retard. Go back to your school". They were very cruel.

H. I wonder what made them behave that way?

P. I assume now that I am an adult that it was taught to them that way. They see us as being segregated and they probably saw the way the teachers treated us. So they figured they don't know nothing so they are nothing.